DOCUMENT RESUME

ED 199 953 EC 132 441

TITLE Proceedings of a National Multicultural Seminar on Mental Retardation among Minority Disadvantaged Populations (Norfolk, Virginia, October 10-12, 1977).

INSTITUTION President's Committee on Mental Retardation, Washington, D.C.

PUB DATE 79

NOTE 124p.

EDRS PRICE MF01/PC05 Plus Postage.

DESCRIPTORS Blacks; Civil Liberties; College Role; Community Services; Delivery Systems; *Disadvantaged Youth; Environmental Influences; Etiology; Genetics; Geriatrics; Health; Intelligence; Mental Health; *Mental Retardation; *Minority Groups; Nature Nurture Controversy; Outreach Programs; Prevention; Public Policy; Puerto Ricans

ABSTRACT

The National Multicultural Seminar on Mental Retardation among Minority Disadvantaged Populations was initiated in response to concern about the root causes of mental retardation especially in mild forms which tend to be more prevalent and more devastating among persons living in depressed, disrupted, and impoverished environments. Nineteen papers from the seminar are provided: "The Issues of Human Rights and Human Services" (W. Robertson); "Prevention of Environmental Causes" (M. Ruiz); "Remarks Made" (C. Kimber); "The Gerontological Aspects of Mental Retardation among Minority Disadvantaged Population" (P. Chang); "Overview and Current Status of the Gerontological Aspects of Mental Retardation" (P. Grob); "The Functions of Community Services Administration" (W. Allison); "Towards Understanding the Need for Minority Participation in the Developmental Disabilities Movement: The Nationwide Study" (B. Morgan); "Reaching the Low-Income Mentally Retarded Consumer" (E. Long); "The Stop Organization Outreach Model" (W. Olton); "The Norfolk State College Model for Service Delivery to Minority Disadvantaged Populations" (R. Woods); "Genetic Studies in the Tidewater Area" (P. Bibbins, Jr.); "Genetics or Environment: Black Intelligence and Attaining our Potential" (B. Bibbins); "The Role of the Predominantly Black College in the Educational Process" (H. Wilson); "The Role of American Colleges and Universities with a Black Heritage" (B. Bulter); "Health Issues Relevant to Mental Retardation in a Multicultural Society" (T. Evans); "Mental Retardation and Mental Health Issues" (R. Sanchez); "The Inter-Relationship Between Mental Health and Mental Retardation" (T. Johnson, Jr.); "Policy Implications for Minority Retarded Citizens" (W. Harris); and "Possible Causes of Mental Retardation in Puerto-Rico: An Island's Challenge" (R. Moran). A summary report titled "Report to the President's Committee on Mental Retardation" by A. Buchmueller concludes the document. (SB)

Proceedings of a National Multicultural Seminar on Mental Retardation among Minority Disadvantaged Populations

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EC 132 441

A NATIONAL MULTICULTURAL SEMINAR

ON

MENTAL RETARDATION

AMONG

MINORITY DISADVANTAGED POPULATIONS

SPONSORED BY

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

AND

THE DEPARTMENT OF SPECIAL EDUCATION

NORFOLK STATE COLLEGE

OCTOBER 10, 11, 12, 1977

NORFOLK STATE COLLEGE

NORFOLK, VIRGINIA 23504

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IN MEMORY OF

Mr. A. D. Buchmueller, a beloved gentleman by all who knew and worked with him died Sunday, October 8, 1978, at his home in Springfield, Virginia. An ardent supporter of human rights development activities for minority disadvantaged populations, Mr. Buchmueller was a member and supporter of the National Minority Affairs Coalition and the recently organized Virginia-MAC Chapter. Mr. Buchmueller assisted in the organization of the Virginia Chapter of the Minority Affairs Coalition.

Mr. Buchmueller's contributions to the awareness process were many and varied in encouragement of the utilization of personnel from predominantly Black colleges, such as Norfolk State in developing appropriate teaching strategies and materials for learners of diverse cultures.

The Minority Affairs Coalition recognizes with appreciation, respect and thanks the contributions made by this esteemed gentleman to the welfare of mankind and express sorrow for the lost of his counsel.

Introduction

The National Multicultural Seminar on mental retardation among minority disadvantaged populations was initiated in response to concern about the root causes of mental retardation especially in mild forms which tend to be more prevalent and more devastating among persons living in depressed, disrupted and impoverished environments. Research results indicated that mild retardation, not involving identifiable organic or physical cause is associated with conditions arising from the environment, poverty, racial and ethnic discrimination and family distress.

One of the goals of the President's Committee on Mental Retardation as stated in the major report MR: 76, Century of Decision, Chapter 5, "Prevention, the Right to a Good Start in Life" is to reduce the incidence and prevalence of mental retardation associated with social disadvantage to the lowest level possible by the end of this century. The Department of Special Education at Norfolk State College is also actively involved in Research, Training and Services to provide resources to prevent and alleviate mental retardation related to economic, educational, social and cultural disadvantage.

The seminar was a working conference and dealt with policy issues, their implications, and recommended models for service delivery. The form of the seminar program evolved from the work of a PCMR Task Force which dealt with the concept of environmental prevention. The theme was "Cultural Diversity as a Determinant in Planning and Providing Programs for Mentally Retarded Persons and their Families."

The President's Committee on Mental Retardation and Norfolk State College invited participation in the seminar to promote the goal. It was not expected that a panacea would be found for all problems of culturally diverse populations. However, it was expected that there would be a positive contribution to improvement of the quality of life of people through the combined efforts of persons with cultural diversity and those from the dominant culture.

A seminar planning committee was selected to ensure appropriate and smooth coordination of the activities. A coordinator was selected from the President's Committee on Mental Retardation and another from Norfolk State College. The Assistant Director of Geriatric Services, State Department of Mental Health and Mental Retardation and the Assistant Supervisor of Special Education, State Department of Education served as Assistant Coordinators of the Seminar.

The participants represented the following areas: Multicultural groupings, geographic disparity, regular classroom teachers, special classroom teachers, administrators, clinicians, counselors, physicians and personnel from various other agencies in this country. Utilizing general sessions and small work group sessions the seminar provided opportunities for interaction between minority and ethnic group persons from the dominant society. It was hoped that this interaction would; (1) develop awareness of the problems confronting persons from diverse

cultures with mild retardation; (2) establish a format for development of more effective communication skills; and (3) provide insights into ways and means that objectives might be achieved.

Objectives

1. To provide information designed to reduce the incidence and prevalence of mental retardation associated with social disadvantages to the lowest level possible by the end of the century through prevention of environmental causes of mental retardation among the disadvantaged.

2. To plan procedures for elimination of prejudicial attitudes and discriminatory practices based on race, ethnic membership or social class as a root source of impaired or retarded human development through programs designed to modify attitudes and social customs of the citizens of America.

3. To provide an open forum for analysis of procedures in planning for improvement of home and community environment and living experience through a consistent attack on conditions which impede or distort full development of human potential among poor and minority groups.

4. To facilitate dialogue among seminar participants toward the purpose of provision of equal educational opportunity for all persons and for enhancement of cultural difference without penalizing and damaging development through analysis of: (a) the economics of mental retardation among the disadvantaged; (b) the politics of mental retardation among the disadvantaged; (c) mental health issues in mental retardation among the disadvantaged.

5. To provide for the development of manpower through the development of indigenous leadership among disadvantaged groups: (a) parental, volunteer, professional and advocacy; (b) vocational and occupational training for the mentally retarded.

6. To recommend necessary controls on the allocation and use of public funds in order to safeguard the interests of the populations at risk from social and economic disadvantages.

7. To plan training programs geared toward replication, modification or reconstruction to accommodate requirements of the mentally retarded disadvantaged citizen with cultural diversity with consideration of approaches to zero-reject education of disadvantaged mentally retarded individuals from infancy through the life span.

8. To extend purpose of previous PCMR conferences on provision for the mentally retarded citizens: to increase awareness among general and special educators and other professionals and lay citizens (consumers) of the central role of ethnicity in particularized programming for the culturally different with mental retardation.

9. To develop understanding of the legal and civil rights of socially disadvantaged mentally retarded people.

10. To recognize the expertise which Black and other minority colleges can contribute to solution of problems of the minority mentally retarded in this country.

It is hoped that through publication of seminar proceedings, the flow of ideas and viewpoints stimulated by the interaction might generate further discussion, research and development among concerned persons who were unable to attend.

Unfortunately, space will not permit the printing of complete presentations. This summary highlights major concerns and viewpoints of the presentors and participants in the small work-group sessions.

Acknowledgements are due to all persons, agencies and organizations at the college, in the local community, the State of Virginia and the Nation who contributed to the success of the seminar. Gratefulness is expressed for your participation.

P R O G R A M

Sunday, October 9, 1977

3:00 - 8:00 P.M.	Registration, Holiday Inn Central
6:00 - 8:00 P.M.	Social Hour (No Host)
7:00 P.M.	Pre-Conference Orientation, PCMR Members and Staff Workgroup Teams: Leaders, Resource/ Consultants Active Listeners, Recorders

Monday, October 10, 1977

8:00 - 9:00 A.M.	Registration and Coffee Front Lobby, Gymnasium
9:00 A.M.	FIRST GENERAL SESSION
Music	Mr. Robert Wynn-Jackson and PERFORMERS Norfolk State College Norfolk, Virginia
Presiding and Introduction of Guests	Mr. Fred J. Krause, Executive Director President's Committee on Mental Retardation Washington, DC.
Invocation	Rev. James C. Griffin, Pastor Bank Street Memorial Church Norfolk, Virginia
Greetings	Dr. Harrison B. Wilson, President Norfolk State College Norfolk, Virginia
	Mr. Vincent Thomas, Mayor, City of Norfolk President, State Board of Education Norfolk, Virginia
	Leo Kirven, Jr., M.D. Acting Commissioner Department of Mental Health and Mental Retardation Richmond, Virginia
	Mrs. Betty Howell, Norfolk City Councilwoman Norfolk, Virginia

Greetings continued	Dr. Woodrow Wilkerson, Secretary Department of Human Resources Commonwealth of Virginia Richmond, Virginia
	Mr. Nathaniel B. Fairfax, Staff Assistant to Dr. G. William Whitehurst, Congressman Second District Norfolk, Virginia
	Mr. David Braswell, President Student Government Association Norfolk State College Norfolk, Virginia
9:45 A.M. Introduction of Keynote Speaker	Dr. Henry Cobb, Vice-Chairman President's Committee on Mental Retardation Washington, DC.
Keynote Address	The Issues of Human Rights and Human Services
	Mr. William B. Robertson, formerly Special Assistant to Governor Linwood Holton and presently serving as Director of US Peace Corps Nairobia, Kenya
10:15 - 10:30 A.M.	Coffee Break
Keynote Panel	Cultural Diversity: A Determinant in Planning and Providing Programs for Mentally Retarded Citizens of Minority Populations
Keynote Speaker and Moderator	Dr. Reginald Jones, Professor of Education; Chairman, Department of Afro-American Studies, University of California Berkeley, California
Panelists	Prevention of Environmental Causes
	Mrs. Marina Ruiz, Director Escuela Especial, Nilmar San Juan, Puerto Rico
	Economic and Political Correlates
	Mrs. N. Lorraine Beebe, Member of President's Committee on Mental Retardation; Chairperson, International Affairs and former State Congresswoman State of Michigan

Panelists continued	Programmatic Concerns and Resources Needed
	Mr. Charles M. Kimber, Director Mental Retardation Program Office Department of Health and Rehabilitation Services, State of Florida Tallahasse, Florida
	Legal and Human Rights for Socially--Economically-Educationally Disadvantaged Persons
	Karen Christensen, Esquire, Civil Rights Division, Office of Litigation US Department of Justice Washington, DC.
12:15 P.M.	Announcements and Instructions to Workgroups
	Dr. Charles E. Flowers Executive Assistant to the President Norfolk State College Norfolk, Virginia
	Mr. A. D. Buchmueller, Program Specialist President's Committee on Mental Retardation Washington, DC.
12:30 P.M.	Lunch - Open
2:00 - 4:30 P.M.	Workgroup Sessions
GROUP 1A Ballroom A, Student Union	Prevention of Environmental Causes-Related Health and Biomedical Issues
Leader/Moderator	Dr. Paul Prince, Director, Psychological Services, Department of Health Commonwealth of Virginia Richmond, Virginia
Resource/Consultant	Dr. Robert Ware, Director of Research Department of Mental Health and Mental Retardation, Commonwealth of Virginia Richmond, Virginia
Active Listener	Mrs. Sylvia Zucker, Executive Director Peninsula Association for Retarded Citizens Hampton, Virginia

Recorder	Dr. Helen P. Bessant, Professor Department of Special Education Norfolk State College Norfolk, Virginia
GROUP 1B Ballroom B, Student Union	Prevention of Environmental Causes- Sociocultural Environmental Issues
Leader/Moderator	Dr. Steward Gable, Director, Child Development Clinic Petersburg, Virginia
Resource/Consultant	Dr. Roberto Moran, Director Special Education Department University of Puerto Rico Rio Piedras, Puerto Rico
Active Listener	Mrs. Laverdia T. Roach, Program Specialist President's Committee on Mental Retardation Washington, DC.
Recorder	Dr. Esther Goldman, Professor Department of Special Education Norfolk State College Norfolk, Virginia
GROUP 2A Ballroom C, Student Union	Economic and Political Correlates- Economic Issues
Leader/Moderator	Dr. William Harris, Dean Afro-American Affairs University of Virginia Charlottesville, Virginia
Resource/Consultant	Mrs. Alexandria Deloatch, Assistant Dean University of Virginia Charolettsville, Virginia
Active Listener	Mr. Bertram Coppock, Director of Program for the Handicapped Robert R. Moton Memorial Institute Washington, DC.
Recorder	Dr. Lillie B. McDonald, Associate Professor Department of Special Education Norfolk State College Norfolk, Virginia
GROUP 2B Room 303, Student Union	Economic and Political Correlates- Political Issues

Leader/Moderator	Mrs. Julia Franklin, Consultant Office of Hispanic Programs, US Department of Housing and Urban Development Washington, DC.
Resource/Consultant	Dr. Azucena Bautista, Associate Professor Political Science Department Norfolk State College Norfolk, Virginia
Active Listener	Ms. Beverly J. Morgan, Project Director Assessment of Minority Participation in Developmental Disabilities Movement New Dimensions in Community Service, Inc. San Francisco, California
Recorder	Dr. Grace W. Setzer, Assistant Professor Special Education Department Norfolk State College Norfolk, Virginia
GROUP 3A Room 319, Student Union	Programmatic Concerns and Resources Needed-Service Delivery Issues
Leader/Moderator	Mr. Vincent Gray, Executive Director District of Columbia Association for Retarded Citizens; Consultant to President's Committee on Mental Retardation Washington, DC.
Resource/Consultant	Mrs. Saundra Rollins, Assistant Director Dept. of Mental Health and Mental Retardation Richmond, VA.
Active Listener	Miss Patricia White, Assistant State Supervisor Special Education Services State Department of Education Richmond, VA.
Recorder	Dr. Vera Small, Professor Department of Special Education Norfolk State College Norfolk, Virginia
GROUP 3B Room 1, School of Social Work	Programmatic Concerns and Resources Needed-Manpower Training and Technical Assistance

Leader/Moderator	Mrs. Irene Wright, Retired, former Dean of Students, Spelman College Atlanta, Georgia
Resource/Consultants	Mrs. Edna Bledsoe, Mental Health Program Specialist Department of Mental Health and Mental Retardation Richmond, Virginia
Active Listener	Esther Stevick, Assistant State Supervisor Special Education Services State Department of Education Richmond, Virginia
Recorder	Mrs. Barbara McCall, Director Instructional Resource Center Norfolk State College Norfolk, Virginia

GROUP 4A

Lecture Room/Technology	Legal and Human Rights-Legislative Issues
Leader/Moderator	Mrs. Yetta W. Galiber, Executive Director Information Center for Handicapped Individuals Washington, DC.
Resource/Consultant	Dr. Dan Payne, Assistant Commissioner Department of Mental Health and Mental Retardation, Commonwealth of Virginia Richmond, Virginia
Active Listener	Mrs. Annie Jo Denny, Executive Director Douglas County Retardation Association Douglasville, Georgia
Recorders	Miss Sheila Scott and Mrs. Lorraine Cuffee Testing Bureau Norfolk State College Norfolk, Virginia

GROUP 4B

East Conference Room-Library	Legal and Human Rights-Judicial Issues
Leader/Moderator	Ms. Michelle White, Esquire, Staff Attorney Massachusetts Department of Mental Health Division of Mental Retardation Boston, Massachusetts
Resource/Consultant	Mr. Miles Santamour, Program Specialist President's Committee on Mental Retardation Washington, DC.

Active Listeners	Ms. Pat Bryne, Chief of Cooperative Services Southeastern Virginia Training Center Chesapeake, Virginia
	Mr. Phillip Estes, Executive Director Tidewater Association for Retarded Citizens Norfolk, Virginia
Recorder	Mrs. Rebecca Parker, Assistant Director Instructional Resource Center Norfolk State College Norfolk, Virginia
5:30 - 7:30 P.M.	Dinner - Open
7:30 P.M. Little Theatre, Brown Memorial Hall	SECOND GENERAL SESSION The Gerontological Aspect of Mental Retardation Among Disadvantaged Populations
Presiding	Mrs. Saundra Rollins, Assistant Director Geriatric Services, Department of Mental Health and Mental Retardation, Commonwealth of Virginia, Richmond, Virginia
Reactor Panel	Dr. Peter Chang, Head, Department of Sociology and Professor of Sociology, Specialist in Aging, Norfolk State College Norfolk, Virginia
	Dr. Paul Grob, Specialist in Aging Old Dominion University Norfolk, Virginia
	Dr. Herbert Marshall, Assistant Director Continuing Education, Specialist in Aging Norfolk State College, Norfolk, Virginia
Floating Resource/ Consultants	Mrs. Edna Bledsoe Mental Health Program Specialist Department of Mental Health and Mental Retardation Richmond, Virginia
	Mr. Arthur Byrd Community Services Coordinator Department of Mental Health and Mental Retardation, Richmond, Virginia
	Miss Margaret Cavey, Director Geriatric Services Department of Mental Health and Mental Retardation, Richmond, Virginia

Floating Resource/ Consultants continued	Dr. Vernon Clark, Associate Professor Department of Health, Physical Education and Recreation, Norfolk State College Norfolk, Virginia
	Mrs. Francis Frazier, Coordinator Community Awareness for Deinstitutionalization Project, The Ohio Association for Retarded Citizens, Columbus, Ohio
	Dr. Jose Duorte, Executive Director Community Health Foundations of East Los Angeles 3945 E. Whittier Blvd. Los Angeles, CA. 90023
	Mrs. Lois Hurdle, Assistant Professor Psychology Department Norfolk State College Norfolk, Virginia
	Mr. Algie T. Howell, Jr. Deputy Equal Employment Opportunity Officer Department of the Navy-Navy Facilities Engineering Command, Alexandria, Virginia
	Miss Esther Shevick, Assistant Supervisor Director of Special Education State Department of Education Richmond, Virginia
	Mrs. Hattie Washington, Instructor Special Education Department Norfolk State College Norfolk, Virginia
Tuesday, October 11, 1977 8:00 - 9:00 A.M.	Registration and Coffee Lobby, Little Theatre, Brown Memorial Hall Norfolk State College
9:00 A.M.	THIRD GENERAL SESSION
	Models for Service Delivery: Policies and Procedures; Necessary Controls to Safeguard Populations at Risk
Presiding	Dr. Henry Cobb, Vice Chairman President's Committee on Mental Retardation Washington, DC.

Keynote Speaker	Mr. William Allison, Deputy Director Community Services Administration, Federal Government, Washington, DC.
Presentor/Panelists	Ms. Beverly J. Morgan, Project Director Assessment of Minority Participation in Developmental Disabilities Movement New Dimensions in Community Service, Inc. San Francisco, California
	Mr. Earl Long, Director, Project Impact, National Association for Retarded Citizens Southwest Region, Burlingame, California
	Mr. Harvey Johnson, Jr., Executive Director Southeastern Tidewater Opportunity Project Norfolk, Virginia
	Mr. Wayne Orton, Associate Director in Charge of Operations, Southeastern Tidewater Opportunity Project, Norfolk, Virginia
	Dr. Roy A. Woods, Vice-President for Academic Affairs Norfolk State College Norfolk, Virginia
12:30 P.M.	Lunch - Open
1:45 P.M. Little Theatre, Brown Memorial Hall	FOURTH GENERAL SESSION Prevention of Mental Retardation: Cricital Health and Environmental Issues
Presiding	Mr. William B. Robertson, Niarobia, Kenya
Speakers	Genetic Studies in the Tidewater Area
	Mr. Paul Bibbins, Cytogeneticist Department of Pathology Eastern Virginia Medical School Norfolk, Virginia
	Mrs. Betty Bibbins, Pediatric Instructor Maternal and Child Care, School of Professional Nursing Norfolk General Hospital Norfolk, Virginia
	Prenatal Care in Prevention of Mental Retardation

	Cecil B. Jacobson, M.D., Geneticist and Member of the President's Committee on Mental Retardation Washington, DC.
3:00 - 4:30 P.M.	Workgroup Sessions (See Monday Afternoon Program for location)
5:30 P.M.	Social Hour - No Host Holiday Inn Central
	Shuttle Buses to College begin at 6:30 P.M.
7:00 P.M.	FIFTH GENERAL SESSION
	Banquet West Campus Dining Hall
Invocation	Rabbi Joseph Goldman, Temple Israel Norfolk, Virginia
Presiding	Mr. Fred J. Krause, Washington, DC.
Program	The Role of American Colleges and Universities with a Black Heritage
Keynote Speaker	Dr. Harrison B. Wilson, President Norfolk State College Norfolk, Virginia
Reactor/Panelists	Dr. Thomas M. Law, President Virginia State College Petersburg, Virginia
	Dr. Bruce Welch, Vice-President for Academic Affairs Virginia Union University Richmond, Virginia
	Dr. James A. Russell, President St. Paul's College Lawrenceville, Virginia
Summarizer/Respondent	Dr. Broadus N. Butler, President Robert R. Moton Memorial Institute Washington, DC.
Wednesday, October 12, 1977 8:00 - 9:00 A.M.	Registration and Coffee Lobby, Little Theatre, Brown Memorial Hall Norfolk State College

9:00 A.M.	SIXTH GENERAL SESSION
	Mental Health Issues in Mental Retardation Among Minority Disadvantaged Populations
Presiding	Dr. Henry V. Cobb, Washington, DC.
Keynote Speaker	Therman Evans, M.D., President District of Columbia Board of Education National Health Director, Operation PUSH Washington, DC.
Panelists	Mr. Rodolfo Sanchez, Executive Director COSSMHO/National Coalition of Hispanic Mental Health and Human Services Organization Washington, DC.
	Mrs. Sophie Thompson, Director Social Services, Navajo Tribal Health Services, Navajo Nation Window Rock, Arizona
	Dr. Turner Johnson, Executive Director North Central Base Service Unit, Mental Health and Mental Retardation Center Philadelphia, Pennsylvania
10:45 A.M.	Workgroup Sessions Preparation of Reports and Recommendations (See Monday Afternoon Program for location)
12:30 P.M.	Lunch - Open
2:00 P.M.	FINAL GROUP SESSION
Presiding	Dr. Ruth W. Diggs, Head Department of Special Education Norfolk State College Norfolk, Virginia
	Workgroup Reports
Moderator	Mrs. N. Lorraine Beebe, Washington, DC.
Conference Summary and Follow-up	Dr. Ruth W. Diggs, Norfolk, Virginia

PLANNING COMMITTEE

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Department of Special Education
Norfolk State College

Mr. A. D. Buchmueller, Program Specialist
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Assistant Director, Geriatric Services
Department of Mental Health and Mental Retardation
Richmond, Virginia

Miss Patricia White
Assistant Supervisor Special Education
State Department of Education
Richmond, Virginia

ACKNOWLEDGEMENTS

We express appreciation to Mrs. Rosalynn Carter, The First Lady of the United States and members of the White House Staff, who provided valuable assistance to the Conference Coordinators in many different ways.

Special thanks to the ladies of the Graduate Chapter of the National Sorority of Phi Delta Kappa, the Kappa Omicron Tau, Sigma Gamma Rho Sorority, the Student Council for Exceptional Children, the Student National Education Association, Alpha Phi Omega, the ROTC, the Spartan Echo and other student organizations who assisted in the planning.

Also, special thanks to the Links, Inc., of Virginia Beach and Chesapeake and the Tidewater Association for Retarded Citizens who made the beautiful table decorations and to the Norfolk Convention Bureau for its assistance in providing badges and badge holders, and other convention materials.

Thanks to the North Carolina Mutual Life Insurance Company for kit favors and the Holiday Inn Central for courteous service to our guests.

To all persons, agencies and organizations at the college and in the community who contributed to the success of this program in anyway, we are extremely grateful for your participation.

GREETINGS

by

Dr. Woodrow W. Wilkerson
Secretary of Human Resources
Commonwealth of Virginia
Richmond, VA.

It gives me great pleasure to extend greetings, on behalf of the Governor's Office, to all who have come to participate in this National Seminar and to welcome to Virginia those who have come from beyond Her borders for this highly significant occasion.

I am delighted that the leadership of Norfolk State College was successful in encouraging the President's Committee on Mental Retardation to bring this Seminar to Virginia.

Our State is a leader in its commitment to appropriate programs and services for the mentally retarded; and, indeed for all with handicapping conditions. We are proud that our Constitution requires the State Board of Education to establish Standards of Quality for the several school districts, subject to review only by the General Assembly.

Our State legislation mandating appropriate education for all handicapped citizens between the ages of two and twenty-one was enacted in 1972, some years before Public Law 94-142 (known as the Education for all Handicapped Citizens Act) came into being.

The Standards of Quality for Public Schools in Virginia include a requirement that each school division shall have a program, acceptable to the Board of Education, for early identification of students who may need special education services.

The standard also says that "when handicapping conditions have been identified, students shall be provided with a program of special education which is acceptable to the Board of Education."

Staff members of the Office of the Secretary of Education and the Secretary of Human Resources recently revised and presented a plan which seeks the earliest possible identification and diagnosis of those with handicapping conditions and those suspected of being handicapped.

There is no doubt in my mind that these programs constitute a sound investment designed to improve the quality of life for our citizens.

I am sure that each of us can sight evidence of much progress in each of our states. At the same time, it is recognized that so much is yet to be done. Many of the major issues that confront Virginia and

other states in their efforts to better serve the handicapped will be discussed during this Seminar.

Greater emphasis must be placed on the prevention of or the amelioration of the causes of handicapping conditions. Such efforts are especially critical where mental retardation is associated with social and cultural disadvantage. Mental retardation, particularly in mild forms, tends to be more prevelent and more devastating among the disadvantaged groups.

Efforts to reduce the occurence of such mental retardation must attack the real causes in depressed and disadvantaged environments. I commend Norfolk State College's Department of Special Education, under the leadership of Dr. Ruth Diggs, upon its involvement in research, training, and services to prevent and alleviate mental retardation to economic, educational, social, and cultural disadvantaged.

The problems are massive, but we know from experience that difficult and complex problems can be solved where there is full commitment. This is what the term, "Prevention: The Right to a Good Start in Life" calls for.

I am confident that this Seminar can lead to a heightened awareness of the crucial importance of focusing concerted effort on prevention and a greater recognition that much can be done. I am confident that you will provide new insight and new approaches into dealing with the basic problems and that your deliberations will be helpful to the states and communities in planning and conducting appropriate programs.

My very best wishes to you as you focus on "Cultural Diversity As a Determinant in Planning and Providing Programs for Mentally Retarded Persons and Their Families".

PRESENTATIONS

THE ISSUES OF HUMAN RIGHTS AND HUMAN SERVICES

by

Mr. William B. Robertson
Director of U.S. Peace Corps
Nairobia, Kenya

Thank you Henry, Fred Krause, Rev. Mr. Griffin, Mayor Thomas, Dr. Wilson, State and National officials, ladies and gentlemen. It is a pleasure for me to be here today, I bring greeting from the President of the United States and his Commission on Mental Health, I bring greetings from the United States Peace Corps and some 13 million brothers and sisters who are Kenyans.

I am pleased to be with the dynamic Dr. Ruth Diggs and talented Alfred Buchmueller, whom I know and have worked with for a number of years. This is a home-coming for me in many ways. I am in my native Commonwealth and am very much at home here at Norfolk State College, Norfolk, Virginia and in some ways my work in mental retardation began in this area--Virginia Beach, Norfolk, Culpepper.

We hold these truths to be self evident that all men are created equal, that they are endowed by their creater with certain rights, that among them are life, liberty and the pursuit of happiness. So spoke Thomas Jefferson, in designing the Declaration of Independence in 1776.

However, for certain segments of our population, these words have had little or no meaning. Some 3% of our population--more than six million citizens know that the word "equality" does not refer to them. We are here at this time and in this place to discuss ways in which we can prevent mental retardation and the manner in which facilities and services might be provided for those citizens who find themselves impaired by this condition.

You and I know the problem is much larger than the six million plus adhered to earlier. Some 85 to 90 percent of those classified as being mentally retarded in non-identifiable organic or physical ways are those who live in poverty. Therefore, we are talking about the plight of those Americans who are Black, Chicano, Puerto Rican, Indian, Oriental and those who are disadvantaged Whites of urban and rural America.

This conference must focus on the problems facing those citizens and report to the President because I am convinced that he is committed to bringing relief to this segment of our population in the name of human rights and human needs.

If we are to tackle the problems confronting the poorest of the poor in America, we must look at employment practices, our educational

system, health care, and racial attitude.

These are not new issues. I have known them since I was born. There have been numerous attempts to eradicate them. The sixties with Martin Luther King, Jr. playing a major role produced a number of changes in the way many Americans live. Yet, today, we find there must be new efforts to bring all Americans into the mainstream. Among many, there is a feeling of hopelessness, the system does not work, the American dream is just that--a dream and nothing more.

The problems of nutrition and health care for all citizens must be addressed at the highest level possible. This means that the President of the United States must lead the fight to bring into being these services--for truly, it is not only a basic human need, but also a basic human right to have a good start in life.

The unemployment rate among Blacks is 13.2% vs. 6.1% among Whites. Black teenage unemployment has reached approximately 40% as opposed to 14.3% for Whites.

It seems that Blacks and other minorities are the last to come into the labor market--last to be hired and the first to be fired. This condition breeds contempt, crime, frustration, loss of dignity and hopelessness. The gaps must be closed if America is to, not only lower the incidences of mental retardation, but assure all of her citizens a share in the American dream.

The public and private sectors must join in this effort. One cannot do it alone. This conference must call for <u>full employment</u> in this country. We must stress to the President that a job is not only a basic human need, but truly a basic human right.

The poorest of the poor have been struggling for improved educational opportunities in this country for what amounts to an eternity. It seems that this struggle in many instances has been caught up in language such as busing, testing and integration. These words bring out attitudes that impede quality education rather than bring about environments in which children learn. Today, we must call for an end to a play on words and demand that there be a return to the basics; reading, writing and arithmetic. Today, we must call for the very best of teachers to be placed in the poorest areas of our cities and rural areas. Today, we must call for parents to join hands with these teachers in order to turn out better products. Our schools cannot be centers of confusion where students and teachers, alike, are afraid for life, limb and property. This will only come about when minorities know that someone cares about the contributions they have made to the development of this country. It seems that what was good in the all Black schools is not acceptable in integrated settings. Black administrators and teachers have been eliminated, schools bearing the names of outstanding Americans such as George Washington, Paul Lawrence Dunbar have either had name changes or have been demoted from high school status to that of junior high or elementary schools.

When minority students think in terms of the days to recognize the achievements and contributions of those who look like them, they

are told this is devisive and it should be done every day rather than single out one day a year or one week a year to concentrate on this type of observance.

But this is not the case for St. Patricks Day nor is it true for Columbus Day which we observe today. Black History week has been observed since 1926--over fifty years, yet, it is the single most controversial time in the school year. While administrators and others do not know how to handle this, it is some sort of threat. Today, we must call for an understanding, an awareness of heritage and diversity which is good and can be shared. Surely, America is a land of cultural pluralty.

Today, we must call for an evaluation of tests to determine how to rid them of their cultural biases. We must determine how test results are used by teachers, administrators, school systems and our society as a whole. It must be determined if they are being used to victimize any segment of our population. Rather than call for an end to testing, we must call for that which takes into account backgrounds, cultures and potential which will serve as tools for better teaching.

If there is true hope for America to demonstrate her desire to provide human needs and support the cause of human rights within or borders, it is in the schools of America. To do less will produce division, the likes of which this country really has not seen. Thank God for schools such as Norfolk State College.

Ladies and gentlemen, I shall not stand here and indicate that progress has not been made in the last fifteen to twenty years because it has. Yet, I do say that for many Americans, this progress has either been too little, or it has not reached them at all.

The American people under the leadership of President Carter must keep the lights on eternally in order to provide every citizen an opportunity to develop, contribute and to live life and live it more abundantly. We have the means - All it takes is the will.

Let this conference go on record indicating that nothing less will be acceptable--that we have gone to the mountain top too many times and have seen the promise land of freedom without being able to enter.

Let this conference say for those of us who live today and the millions yet unborn who are minorities in this country that each of us will enter the valley of freedom and partake of the nectar of liberty and as we do this, we do indeed reduce the incidences of mental retardation. It will be then that our hearts will swell and the words of James Weldon Johnson will take on new meaning. Our rejoicing shall rise - high as the listening skies - It shall resound loud as the rolling seas, because the elusive American Dream shall at last be yours and mine.

PREVENTION OF ENVIRONMENTAL CAUSES

by

Mrs. Marina M. Ruiz
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and Vocational Training of
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Good morning, members of the President's Committee on Mental Retardation, members of Norfolk State College, fellow speakers, ladies and gentlemen.

I am Marina M. Ruiz, from Puerto Rico. I am very honored to have been invited to participate in this National Multicultural Seminar on Mental Retardation Among Minority Disadvantaged Populations.

Before proceeding with my presentation on the Prevention of Environmental Causes of Mental Retardation, I would like to tell you something about Puerto Rico.

Puerto Rico is an island 36 miles wide by 100 miles long, located in the Caribbean area. It is the largest of the so-called Minor Antilles.

Our population is approximately 3,223,800.[1] Our government is constituted as a Commonwealth. We are American citizens, and our currency is the U.S. Dollar. We are bilingual, but our main language is Spanish.

Until 1940, the economy of Puerto Rico was primarily agricultural, based mainly on the growing and harvesting of sugar cane. This has dramatically changed since then. Manufacturing, industrial and commerical activities are now predominant and account for most of our economic life.

It is painful to admit that, within such a beautiful setting, like in so many other places elsewhere, there should exist environmental causes of mental retardation that afflict a large number of the Puerto Rican population.

It should therefore, be our commitment to safeguard our environment against such causes and thus help to achieve the goal of "Prevention, Right to a Good Start in Life", stated by the President's Committee on Mental Retardation.

To accomplish this we must first discover and define such causes. They are mainly the following in the case of a Minority Disadvantaged Population like that of Puerto Rico. (1) Over population is a basic environmental cause of mental retardation. Trauma at birth, genetic

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[1] Statistical Report on the Population Census of Puerto Rico (1976), Registry of Vital Statistics, Department of Health of Puerto Rico.

disorders, cerebral anoxia and other syndromes which engender mental retardation are not always duly overcome as adequate medical facilities and services are not readily available in all cases; (2) Poverty can be classified as an environmental cause of mental retardation. It has been observed that mental deficiency has an elevated incidence among the poorest human groups and numerous investigators have indicated that the level of intellectual performance in children coming from a low socio-cultural class is inferior to that obtained by children of the same ethnic group, but who come from the middle or the high socio-economic class. Eighty percent of families in Puerto Rico received an annual income of less than $3,000; (3) Low unhealthy conditions may be mentioned as another environmental cause of mental retardation. Thousands of adequate housing units have been provided, however, it is estimated that Puerto Rico still needs 250,000 additional housing units for low income families; (4) Unemployment should be considered an environmental cause of mental retardation since unemployment means a lack of income, despair, alcoholism and drug addiction. Mental retardation is believed to be engendered when one or more of these conditions are present. In Puerto Rico, the unemployment rate is now approximately 23% of the labor force; (5) Parents with low scholarity or illiteracy are generally unable to seek assistance and information on the prenatal care of the mother and during childbirth; (6) In-breeding may be a cause of mental retardation in Puerto Rico. Being an over-populated and small island, the incidence of in-breeding is high; and (7) Contamination and pollution due to industrialization and urban development have resulted in the contamination and pollution of the physical environment. Exposure of women to this type of environment may result in injury to the fetus.

Recommendations

1. Prevention against overpopulation as an environmental cause of mental retardation can be accomplished by family planning programs and education of the population on the responsibilities of parenthood.

2. It is very hard to eliminate and prevent poverty. However, the evil effects of poverty can be and are being ameliorated through the enforcement of several federal and local welfare and health programs. Food stamps have undoubtedly helped to improve nutrition for, besides providing the means to purchase, good basic orientation is given on what the daily diet should be.

3. Provide more low cost housing to alleviate low healthy conditions.

4. Provide more employment opportunities through (a) implementation of a large scale of public works (b) revitalization of agriculture and restructuring of the industrialization program; and (c) seek assistance from federal sources.

5. Develop community awareness programs and improve the orientation of social workers and improve educational facilties to help prevent mental retardation due to low scholarity.

6. Develop adequate family planning programs and provide widespread genetic tests.

7. Enforce federal and local laws and regulations for the control and protection of the quality of the environment by (a) ensuring and providing adequate protective equipment for workers; (b) ensuring constant maintenance and repair of equipment and machinery to prevent contamination of area where industry is located.

PRAGMATIC CONCERNS AND RESOURCES NEEDED

by

Mr. Charles M. Kimber
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Florida Department of Health and Rehabilitative Services
Tallahassee, FL

Thank you for the enjoyment of being here today. It's a distinct pleasure to participate with such a group of distinguished individuals in pursuit of strategies for serving disadvantaged minority populations.

"The Right to a Good Start in Life", is the Committee's theme. Our vital purpose and ultimate goal could not be more succinctly summarized. The premise is as fundamental as the essential principles of our existence. To realize life, liberty, and the pursuit of happiness, we follow a course charted within a realm established even before birth. When you are deprived by disadvantage and are mentally retarded, the realm can be a composite of inescapable malignance.

CHARACTERISTICS AND CAUSES PREVALENT WITHIN THE CULTURALLY DISADVANTAGED GROUP

A culturally disadvantaged person is one who has been subjected to a particular set of experiences which cannot effectively prepare him for success or even survival against the demands of the norm. The individual nurtured in the throes of poverty, oppressed by racism, isolated by ethnic differences will no doubt be culturally disadvantaged.

Mentally retarded persons most commonly fall within this realm of culturally disadvantaged. We find 85 to 90 percent of mild retardation recipitated by environmental circumstances such as racism, poverty and ethnic differences...factors which result in cultural problems.

According to the available literature, the disadvantaged preschooler tends to have a lower I.Q. measurement and tends to be about a year behind in language development. His strengths will probably be in memory span and rote learning. The disadvantaged child is likely to come from an environment in which his models appear hopeless or powerless to improve their own situation. His goals would tend to be short ranged and restricted.

A PHILOSOPHICAL FRAMEWORK FOR SERVICES

The educational environment is looked upon as the compensator for the cultural deficit, hence, the schools have been the focal point of

all of our major integration efforts. In the landmark supreme court decision, 1954, Brown v. The Board of Education, the late Chief Justice Earl Warren wrote that, "It is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education." Such an opportunity where the state has undertaken to provide it is a right which must be made available to all on equal terms." Unfortunately, we have managed to circumvent some of the intent of that historical decision.

Service providers must also alter the environment to be accepting of the individual. An approach we can call Human Ecology. In an accepting environment when everyone around him has strong educational motivation, a disadvantaged child will achieve. His success will be fostered by warm support and rewards. The learning environment must be stimulating and experiential. Many of those experiences will often need interpretation.

SPECIFIC STRATEGIES, TECHNIQUES AND NEEDED RESOURCES

How do we serve the culturally disadvantaged minority person? Our intervention must be at the earliest point possible, with infant stimulation programs and parent training. We must make prudent professional use of our diagnostic and screening instruments. Our diagnostic activities must be culturally fair, must reflect an assessment of the whole individual through a multi-disciplinary approach and must include functional evaluative criteria.

Unfortunately, among minority citizens, there may be a lack of knowledge about the available screening and counseling services. Our services must provide continuity between the service and the home, involving the parents and siblings. Unfortunately, many of our teachers may have low performance expectations of culturally disadvantaged individuals. Those low expectations are in themselves an impediment.

Skills development must be the backbone of our efforts. In young children we can increase the level by targeting in on sensorimotor development, communications, socialization and self-help skills. In adults, we must emphasize academics, adaptive behavior and cognitive behavior, as well as interpersonal relationships, vocational guidance and social responsibility. Where possible, and practical, we should mix the retarded disadvantaged child with intellectually normal peers-in-day care, child development centers, foster homes and academic settings.

We must have strategies for working with the culturally disadvantaged. They must be based on an understanding of the individual from a diagnostic, cultural standpoint--a standpoint able to sequence out the appropriate motivators and reinforcers of the developmental experience.

We must involve parents and peers--and foster independence in a warm, rewarding, receptive environment.

Our service arena must insure a right to a good start in life--with prevention through genetic counseling, prenatal care, fetal care, nutrition, screening and diagnosis, parental counsel, training in vocational, academic and social adaptation.

We must rely on the resources where available...nurture the resources where untapped...and cultivate the resources where unpresent.

We must capitalize on the capabilities of the universities, particularly Black universities and the university affiliated facilities (UAF). We must rightfully depend upon schools, the churches, the health service groups, the legal services, the recreation departments and the integrated human service systems, such as Florida's Health and Rehabilitative Integrated Human Services Agency.

It is an enormous challenge--much of it rests with people like you. People who can truly make a successful impact in serving minority, culturally disadvantaged persons by spreading the word through work seminars, public information, legislative activism and human advocacy.

John Dewey once said, "The ideal of Equality is that every human being warrants equal consideration of his needs and his wants."

It's our job to assure that this equality uncompromisingly extends to those who are retarded and those who are culturally disadvantaged.

THE GERONTOLOGICAL ASPECTS OF MENTAL RETARDATION AMONG MINORITY DISADVANTAGED POPULATION

by

Dr. Peter Chang
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Norfolk, VA.

I really feel honored for being given an opportunity to share some ideas with you with regard to gerontological aspects of mental retardation among minority disadvantaged populations. First of all, when we discuss minority problems we must not let our emotions take over. We must follow our rational reasoning. In other words, we must be objective in assessing the present situations or systems which either promote or impede the progress in treating minority mentally retarded persons.

The topic of this session is a very complicated one. Gerontology is a fairly new discipline, gerontological aspects of retarded persons is very new, and gerontological aspects of minority retarded persons is the newest of all.

Gerontological studies and researches have not paid much attention to minority aged until the second White House Conference on Aging in 1971. In the same year, the National Caucus on Black Aged was organized with the main purpose of promoting the quality of life of the Black aged. It is common knowledge that all the other minority aged have been brought to the public attention because of the leadership played by the National Caucus on Black Aged.

Before 1970, there were only a few articles, master's theses and Ph.D. dissertations on the Black aged, although in the past few years the literature on Black aged has increased, yet its increase has been less than anticipated, due to the lack of research funds.

In 1974, the National Center on Black Aged was established. One of the purposes is to collect and disseminate all available information on the Black aged. It is my hope that they will receive enough funds to be able to reach the goals they established.

How about information on other minority aged? The situation is worse. There are only a few articles, Ph.D dissertations and research projects on them. I am certain that there is very little information available and research done in the area of minority mentally retarded aged. Here we are talking about aged persons in minority groups, not about the aged as a minority group.

However, we do have some knowledge about minority groups. In the United States, a minority group has the following sociological charac-

teristics: Low social and economic status, being descriminated against, powerless, and group consciousness. The minority group forms a sub-social world or a sub-culture which is distinguishable from the majority, because each sub-culture has its unique value system, normative structures, behavior patterns, and meaning of life in which people are growing old.

At the present time, it is hard to find the demographic characteristics of the minority mentally retarded aged. In order to increase our information and knowledge about them, provide adequate and appropriate services for them, we should know who they are, where they are, what are the degrees of their mental retardation. Some of them are born retarded, others become retarded due to longer stay in the state mental hospitals, or due to the aging process. What are their life expectancy?

It is may personnal guess that many minority families are trying to hide the retarded members from the agencies. They will not report them unless they are in the severe state of retardation. What are their life styles if they are living in the community? What percentage of them are living alone? Where do they get economic, social and emotional support? All these relevent informations will aid our understanding and help devise appropriate programs and services for them.

Funds are needed for research and services in the area of minority mentally retarded persons, both young and old. The needed funds will not be coming until we have a strong advocate organization for these groups with multiple jeopardy--being a minority group member, old, mentally retarded, dependent.

In conclusion, I quote a statement made by Dr. James H. Carter:

> "Historically, there have been three lines of approach to the treatment of mental illness--the physical, the psychological and the social. While all three forms of intervention are utilized to some extent, at the present time it is characteristic for Black patients to receive the only physical approach (chemical-somatic). Conditions of life of the Black patients, particularly from low income families, are such that a simultaneous attack on all levels is frequently required."

The following are a few suggestions:

1. More research is needed in the area of minority mentally retarded aged.
2. Life cycle of minority groups should be introduced into the curriculum, including the characteristics and problems they face in different stages of the life cycle, so that we may devise strategies of intervention or prevention.
3. More trained professionals are needed to provide services for the minority mentally retarded persons.
4. More appropriate services are needed to meet the specific needs of the minority mentally retarded persons.

OVERVIEW AND CURRENT STATUS OF THE

GERONTOLOGICAL ASPECTS OF MENTAL RETARDATION

by

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One measure by which a society's humaneness can be determined is the concern and responsibility it manifests for its aged and handicapped (Heschel, 1971). Since the first WHCOA (1951), there has been a growing awareness of the elderly as a significant numerical and proportionate segment of society. Numbering almost 30 million (at age 60+) they are like other subgroups, held together by some shared values and beliefs, systems, concerns, needs and history, yet hardly homogenous because of diverse origins, cultures, levels of education, conditions of health, mother tongue and economics. While initially administrators and planners designed programs in accordance with the simplistic and seductive myths of homogeneity, it is the diversity of the needs of the aged upon which service providers and planners are focussing currently.

Interest and activity in mental retardation paralleled that in aging, in that it too spurted forward shortly after World War II and accelerated also almost simultaneously (during and following the Kennedy Administration) and emanated initially from those most directly concerned with responding to special needs (i.e. families and some service providers).

Also significant and often confounding is the problem of defining age boundaries for the aging retarded. While for the population at large ("normals") the position of aged often coincides with the frequent mandated separation of man from the world of work (i.e. between ages 60-65), retirement in and of itself is not a significant milestone for the mentally retarded. Most often it does not occur at all because of a general absence of a conventional or lengthy employment history.

In addition to retirement, the onset of aging is regarded by many as influenced by several degradative factors which include declines in physical and mental capacities, loss of income potential and often the inappropriate utilization of increased leisure time. (Atchley, 1972). Except for earlier chronological onset, the losses observed among the aged retarded parallel those of the aging at large in that they also experience increased physical impairment, decline in mental function, low or non-existent income, a sense of personnal loss and family rejection, and time in which little that is worthwhile occurs. (Kriger, 1975).

While it may be useful to draw some parallels, it would be naive to overlook the fact that major differences in life experiences exist

for the mentally retarded who become aged and for the person, who because of developmental losses of trauma becomes cognitively impaired in his senium. Continuing (and as yet unpublished) research which includes groups in Virginia and in Palo Alto, California, reveal that elderly mentally retarded, more than the elderly at large suffer from a profound sense of loss. There is an awareness not only of having missed much of what is available to the population at large, but even more depressing and degradative, of never even having had a chance at it. Erik Erikson's last stage on the continuum of life development from ego-integrity to ego-dispair is poignantly illustrated by the older mentally retarded who has also come to the realization that he will never experience the relationships which pervade the environment at large and in which his normal elderly peers engage.

Scientific and more specifically, medical knowledge has taken a quantum leap since the 1930's with the consequence of a significant reduction in both infant mortality and accompanying childhood diseases. The mentally retarded and other handicapped are also among those benefiting from these advances and arriving at old age. The emergent national concerns for the elderly at large sparked the development and convocation of the First National Conference and Consultation on the Gerontological Aspects of Mental Retardation. The combined efforts of the University of Michigan's Institute of Gerontology and the Study of Mental Retardation and Related Disorders at Ann Arbor focussed national attention on the needs of elderly retarded and their families for related professionals (service providers, planners, teachers). Despite the mandate to assemble and provide data relevant to their own geographical location, few of the seventy participants arrived with any significant information. Some of the problems encountered by the participants included the following:

1. No information on Mental Retardation was listed centrally in any of the states represented by conference participants.
2. When information was available, mental retardation tended to be considered dichotomously, either as minors (below age 18) or as adults, (18+) rather than according to 5 or 10 year intervals as are other groups in the population at large (e.g. 25-29; or 59-69).
3. The difficulty in defining "aged" as related to mental retardation was observed prior to the first conference and persisted throughout the conference.

While age definition could constitute a research barrier, the absence of any demographic investigation and the consequent lack of pertinent data emerged as the most significant concern. Kriger (1975) indicated that while all 50 states were surveyed, only 3 of 33 states responded with any usable data. Some of the findings included:

1. Many states kept no statistical information on mentally retarded.
2. When information was available age ranges were too ambiguous to derive meaning.
3. Many states reported only extrapolated data which indicated that the number of mentally retarded declined rapidly after age 45.
4. Information about retardates receiving services was often not available.

5. Reports on available services often indicated they were underutilized.

Four general types of programs and services were described by Kriger in the Ohio study and by other participants. They included the following:

1. Residential Service Programs and Services which offered the mentally retarded low cost housing, private apartments or rooms, foster homes, group homes, half way houses, nursing homes or other institutional care in the absence of facilitative parents or siblings.
2. Day Care Activities and Programs located at day care centers or schools and comprised of educational and other skill training, work activity (e.g. sheltered workshops) and vocational rehabilitation.
3. Auxiliary Services offering therapeutic or remedial health programs in addition to counseling, evaluation and diagnosis.

While the existence of residential community based services were reported, evaluation of program effectiveness was either unavailable or not discussed meaningfully. The assumption of Skarnulis (1974) that community based services excelled those offered in residential settings could not be verified.

One of the most significant findings of the conference was that aged mentally retarded are few in number.* Several challenging questions were voiced reflecting concern about survival rates of mentally retarded both in residential and community based settings. Do they still fail to survive in significant numbers? Why? Are the community based mentally retarded who complete education and training programs lost from the number pool because of their ability to blend in with the social milieu?

There is no doubt that the regressive stressors in society at large are experienced by the mentally retarded as well and hence many fail to survive. In addition, the lack of demographic systems for the purpose of identifying and keeping track of mentally retarded by age and other significant variables does not allow for identifying aged mentally retarded accurately.

It might be of worth to reflect briefly on a project completed in 1976 in which aged and younger institutionalized mentally retarded were facilitated in their reintegration into the community through the efforts and talents of senior citizen advocates. The Senior Advocacy Program (SAP) addressed itself to the needs of both groups (i.e. to provide training and employment for senior citizens and to enhance the adjustment of newly released mentally retarded to the world of work and to the performance of many daily activities most of society takes for granted. The project is fully described in Senior Advocacy Program for the Developmentally Disabled Adult, (Schapiro and Grob, 1976).

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*Kriger adopted 45 as appropriate for aged mentally retarded.

It is the writer's belief on preliminary findings that the arbitrary age of 45 is inappropriate as the cut off point to identify aged mentally retarded. In addition, many of those identified as aged institutionalized mentally retarded were most likely mislabeled upon entrance and should not fall into the category of mentally retarded or developmentally disabled adults, albeit their current cognitive functional level. The need for continued research is irrefutable.

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THE FUNCTIONS OF COMMUNITY SERVICES ADMINISTRATION

by

Mr. William Allison
Deputy Director
Community Services Administration
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I am very glad you invited me here today. Mental retardation and the problems it brings to individuals and families are extremely important in the overall concern of my agency, the Community Services Administration. The goal of our programs, to eliminate poverty, necessarily encompasses an effort to reduce the incidence and effects of mental retardation. I was very pleased to see that the President's Committee report, "Century of Decision", expresses support for continuation of the Community Action Program. Obviously, the Committee also realizes how closely our interests parallel each other.

Community Action is the principal program of our agency. For those who may not know what it is and does, the name really tells it all: Communities determine what problems need working on and set about solving them. CSA provides interpretation of the legislation, regulations as to use of the appropriated funds, technical assistance in working out some parts of the plans and the grants that support basic Community Action Programs, (or CAP's). Programs are localized from beginning to end. Local people, including those who will benefit from the program, do the planning and directing. Since each community is different from every other, the plans vary tremendously. However, there are some elements that appear everywhere. Every CAP tries to work as close as possible to the poverty population of the area. It does this by reversing the old traditional method of service delivery, in which an agency would set up its office in a place convenient for the staff, announce its presence and then wait for people to come and find it. The CAP, on the other hand, finds an area where needs are great and sets up shop there, in what are called "neighborhood centers." A large program may have a whole network of neighborhood centers. A rural area may be served by mobile units. In any event, the point is that the service is taken to the people who need it. Going further, word about the services is carried, sometimes literally from door to door, by Outreach Workers, many of whom are recruited from the so-called target group. (Never really cared for the idea of calling a group of people a target. That's why the "so-called".) By working closely <u>with</u>, not just <u>for</u>, the area's residents, building trust on that contact and more intimate contact on that trust, the CAP acquires a unique ability to ferret out and deal with problems, even those problems that escape or are hidden from professional social workers and teachers.

Another universal feature of Community Action Programs is a dedication to resource mobilization. Virtually every grantee of the Community Services Administration also receives funds from other federal

departments as well as state and local agencies and blends its activities into packages that best fit the needs of the people. It also develops relationships with other service providers of all kinds, so that referrals can be made quickly, with a minimum of trouble to the needy person.

Of course, I have just described the ideal Community Action Program, and we all know that varying conditions and human personalities rarely permit the ideal. In reality, the sort of resource mobilization in which the CAP is both a catalyst and an active agent is, at present, still evolving. We might say that the evolution began to look possible in 1965, when Head Start first appeared. In order to provide the medical, nutrition, education, social and other services that were the major components of Head Start, the CAPs had to draw on sources other than our agency--then known as OEO.

It was also that program that brought us our first contact with mental retardation--or perhaps I should say apparent retardation. Head Start uncovered deprivations never before seen by better-off social scientists: Five-year-olds who had never seen themselves in a mirror, who couldn't figure out how to turn on a water faucet, who tried to eat potato chips with a fork, or who used a spoon for all foods. These were actually observed instances. Many of those children were immediately labeled retarded by teachers and aides who could not begin to understand the empty environments the kids called home. Then, with exposure and growing understanding, they saw the apparent signs of retardation begin to disappear.

It is true, that thousands of Head Start children have been retarded. If it hadn't been for this program, if Outreach Workers had not gone to their homes and convinced their reluctant parents to open the door, some of them would still be rocking in some forgotten corner with no hope for anything better. But because of Head Start, because of the interlocking connections between the CAPs and the schools, the medical profession, local chapters of NARC and other interested organizations, those children are no longer without hope.

Since those early days, the CAPs have found other ways to serve the needs of mentally retarded persons. In Garrett County, Maryland, the Community Action Committee operates a combined sheltered work and training facility. The training includes independent living skills. Several of the graduates are now managing their own lives in the community. Gleams Community Action, based in Greenwood, South Carolina, provides diagnostic and evaluation services for mentally retarded children and adults. People are referred to school systems, vocational rehabilitation or other appropriate agencies, but Gleams continues contact to see that they are receiving the necessary services. Gleams also offers a sheltered workshop for the severely retarded, speech therapy for adults and training in independent living skills. Project Handicapped Advocacy in Lauderdale County, Florida, is an outstanding example of catalytic action. Its principal service is problem solving. When an Outreach Worker encounters someone who needs help, he/she checks with the Advocacy staff and finds out where to take the person.

When a service agency comes across an unusual or complicated case,

(such as someone who is both mentally retarded and deaf), Project Handicapped Advocacy is called in to find a solution.

Using another approach, our San Francisco regional office has, for three years, funded a project at NARC's Burlingame, California office. It provides outreach and service coordination through local Associations for Retarded Citizens. The CAPs in the Service areas are involved only as potential service providers. But, Mr. Earl Long, the Project Director, is also on our panel and will tell you more about their work.

These are just a few illustrations of how Community Action can contribute to better service for the retarded. There is a world of room for more cooperative efforts, and I am confident that most CAPs would eagerly participate. I urge all professionals in this field (and to me a professional is anyone who knows his job well, regardless of degrees or level or work) to visit your Community Action Agencies, get to know their staffs and their capabilities and share with them your ideas on needs and programs. Furthermore, I urge you to introduce the CAP staffs to your mentally retarded friends and clients. They can better serve the needs and participate in the programs if they know the beneficiaries as people, not just statistics or case numbers. I should warn you, though, that most CAPs are already stretching their budgets to the limit. So along with your suggestions, I hope you can offer some volunteer workers or even some dollars.

I came to CSA after several years as Director of the Community Action Program in Atlanta. I know the tremendous service delivery potential that lies within these local organizations. The field of mental retardation may seem too technical or even unrelated to some program directors--but so did legal services and energy conservation at one time. Our agency and our grantees went into those and were very successful. I hope that, in a few years, we can say the same about this field.

TOWARDS UNDERSTANDING THE NEED FOR MINORITY PARTICIPATION

IN THE DEVELOPMENTAL DISABILITIES MOVEMENT: THE NATIONWIDE STUDY

by

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INTRODUCTION

In preparing this presentation for you today on our study on minority participation in the developmental disabilities (DD) movement, I explored several ways for introducing the discussion.

First, I thought about beginning with a comparison of the human service system to the political system, which someone once described as the struggle for answering the question: Who gets what, when and how? And if we look at the fierce discussion going on around which disabilities ought to be included in DD, I think we could conclude that the discussion borders on a debate of who gets what, when and how: i.e., which disability (who) will be included in order to be eligible for federal funding (what) within the next years (when), though the grant mechanism (How).

Then I thought about sharing with you a recent experience our organization had in reviewing one of the 1978 State DD plans. We were asked to comment on this plan and gathered data which indicated that the State whose plan we were commenting upon had a minority population which was 26% of the State's total. And using incidence figures prepared by that State's DD planners, we projected that over 200,000 minority persons had DD in that State. So when we received a copy of the plan, we were anxious to see what kind of attention was given to this sizable DD population. Since a large number of the minorities were Asian, we expected to see plans for hiring these persons as trainers, planners, etc. Since this State had a large migrant and Spanish-speaking population, we expected to read about use of bilingual materials, outreach, etc. We saw none of these things.

Since we know that people understand that planning is essentially a process involving decisions and activities around "getting to there from here", we were unable to understand why sizable minority populations were not included in this important planning document and we thought about Moynihan's phrase; "benign neglect."

Then I thought neither of these approaches would accomplish what I want which is to assist some of you in understanding the need for minority participation in the DD movement, and more specifically, the need for our study. (We know that there is a need for understanding by the correspondence and calls we get which question why it's necessary to

assess minority participation. We know the study is needed because no where is there any information gathered on a systematic basis which examines minority participation).

I recently attended a workshop where the impact of a disabled child on the family unit was discussed. And I want to share with you some comments on how parents cope. Now I know many of you already understand the coping process as many of you are parents, or brothers, or sisters, of a disabled person. But let me describe the coping process anyway. There is that first stage that parents, friends, or relatives go through when they learn their child is not as they expected it to be...and, there is grief for the kind of child, sibling, niece, nephew, cousin, or godchild that was wanted but did not come...there is denial...there is false hope...yes, it happened, but he/she will get better. There is guilt, anger, intellectualization and finally, acceptance and realistic planning. This is the coping process. A family can get caught at any one stage for weeks, months, or years.

How agencies facilitate and assist parents progress and movement through this process is essential for the eventual treatment and planning for the child.

Isn't it possible (based on writings on minority families by Billingsley, Hill, Perkins and others) that minority families (and in this instance, Black families) have cultural and ethnic factors which may cause certain stages in this coping process to last longer or be more intense or totally debilitating? Isn't it possible that the self-image of the Black male may be so shattered by the experience of parenting a disabled child that an approach to counseling which initially focuses on his needs and reactions is more relevant than one which involves only the mother?

The answers to my questions necessitate an understanding and sensitivity to differences resulting from cultural and ethnic factors. For if we achieve nothing but the hiring of more minorities as staff in DD agencies, at least these agencies will be exposed to minorities and, hopefully their sensitivity and awareness will increase and improve. This, to me, is what the need for minority participation is all about.

NATIONWIDE STUDY

Now, about our nationwide study. In discussing the study with you I will highlight three areas; our objectives, the methodology and survey design, and our preliminary findings from Year 1.

Objectives of the study. New Dimensions in Community Service, Inc. received the grant to conduct the two-year study in October, 1976 from the Office of Human Development, Developmental Disabilities Office, Department of Health, Education and Welfare; Washington, DC. The organization is under the direction of Mrs. Naomi Gray.

In developing the study's objectives, we were cognizant of DHEW's concern as stated in their REP that the study should yield documentation on the State-of-the-Art in the developmental disability field as regards

the involvement of minorities.

Thus, our objectives are:

1. To conduct a nationwide fact-finding study on the numbers of minorities participating in planning and implementation of DD services.
   a. To identify agency procedures for recruiting minority ideas and receiving input on service needs
   b. To compile recommendations for change
2. To assess the level of minority participation
   a. To compare agency and community perceptions of minority involvement and needs
   b. To assess strategies for increasing minority participation and making it more effective
3. To make resource and study information available to agencies and communities
4. To recommend a plan-of-action for state DD planning councils and other policy and planning bodies to increase effective minority participation in their decisions.

There are some definitions you should be aware of in our discussion. These are:

"Minority" - includes Asian, Black, Native American and Spanish-speaking/Surname Americans.

"Participation" - is defined as involvement by minorities as staff, consumers (users of services), and/or members of boards or committees having input in the DD service system.

"Developmental Disabilities" - are defined in Public Law 94-103 of the Developmental Disabled Assistance and Bill of Rights Act. It includes, but is not limited to, autism, cerebral palsy, epilepsy and mental retardation.

"Service" - is the direct or indirect provision of help and assistance or the transfer of information or materials by public or private agencies, groups, or organizations to DD persons and their families.

"Movement" - includes those agencies, groups, or organizations which provide services or advocate the support or distribution of such services.

Methodology. Methodology: The study is essentially a fact finding project.

We interpret facts in two ways: First, in terms of data, i.e., the numbers of persons on staff, the numbers on boards, etc. However, we also understand that if people perceive things to be a certain way and if they respond as if things were that way, even if in actuality they are not, then these perceptions are facts to them.

So, in designing the methodology, we sought ways of obtaining data on both sets of "facts".

There were (and remain) several unknowns for the study. For example, how many minority persons have DD? How many are using agency services? The number of agencies serving the DD population? How many minority DD are in State hospitals? How many are in their own homes?, etc.

These unknowns and our definition of "facts" necessitated our developing a study approach which is not designed to test any hypothesis but which is best described as survey research. Thus, our study approach emerged with two methodologies:

1. We would obtain information on perceptions via a series of meetings throughout the country.
2. We would obtain data on numbers of minority persons involved (on boards, as staff, etc.), via a questionnaire.

Let me discuss the survey design for the questionnaires first, then I will discuss how the meetings were implemented which leads into the discussion of Year 1 findings.

There are three questionnaires which will be mailed nationwide in January, 1978; one for minority persons who are parents of DD Children; one for minority persons who are DD; and one for providers of services. The sample size for minority persons is 1,000. Five thousand (5,000) agencies/organizations will be included in the service provider sample. The questionnaire to providers of services will focus on:

1. Total number of minorities working with DD service agencies
2. Number of minorities in management, line staff, or volunteer positions, on advisory or policy committees or boards
3. Current agency procedures and programs to involve minorities and receive minority input
4. Subjects on which minority input is being received
5. Subjects on which minority input is thought to be needed
6. Perception of greatest service needs of minority populations
7. Successful strategies for increasing minority input into decision-making and planning
8. Existence of outreach programs using workers from the target populations
9. Availability of bilingual materials
10. Use of media and other educational programs to inform and recruit minorities

The questionnaires to the parents/consumers will focus on:

1. Their understanding of DD and the kinds of disabilities they and/or their children have
2. Their participation as consumers of services and decision-makers
3. Their perception of barriers to services
4. Their satisfaction with services
5. Ways they discovered services and types of groups/organizations which were most helpful to them as they sought services

6. Whether they feel being a member of a minority population has helped or hindered them in obtaining and learning about services

To insure responses from minority client/consumers, we have identified what we call questionnaire facilitators. These are minority persons who participated in our meetings and who indicated a desire to work with the study and a concern to obtain information from those parents unable to attend the meetings. These facilitators will identify and assist persons in completing the questionnaire.

Both the client/consumers' and service providers' sample will be stratified according to the proportion of minorities within each of the ten U.S. regions. For example, Census data indicate that Region IX has 11% of the U.S. minority population. Therefore, 11% of the client/consumer sample and 11% of the service provider sample will come from Region IX.

If we had accurate prevalence (rate at which a condition is found within a population) and incidence (rate of the initial occurrence of a condition) figures per region for each of the minority populations, we would be able to further stratify our client/consumer sample. Unfortunately, these figures are not available.

The same is true for the service provider sample. If we had data per region on the number of agencies serving the disabled, type of service offered and the type of agency offering services, we would be able to stratify based on these factors.

For the service provider sample, we will attempt to get a "representative" sampling of agencies providing services by type of disability (e.g., epilepsy, autism, etc.), as well as public agencies and private agencies and those involved in direct services versus those involved in information and referral or advocacy activities only.

The names of parents/consumers came primarily from two sources:

1. Service providers (e.g., State DD Councils, United Cerebral Palsy, National Assoication for Retarded Citizens, local agencies, etc.)
2. Various organizations which are concerned about the quality of services to minorities (e.g., Welfare Rights Organizations, Urban League and its Affiliates, Aspira, Inc. (a Puerto Rican Group), etc.

Undoubtedly, the names from service providers represent client/consumers who are currently receiving services. The names gotten from the other organizations are probably "individuals needing services". Thus, we feel we will have a balanced sample of persons in and outside of the DD service system.

I have presented this rather lengthy discussion on the methodology because I want you to understand that ours is more than a look at affirmative action. We are attempting to examine the DD service system,

(both scope and quality of services), using the minority consumer as the valuator.

The other methodology used in our study was the series of meetings mentioned earlier. We held 31 meetings in 14 cities throughout the country during January, February and March, 1977. The focus of these meetings was two-fold:

1. To obtain minority parent/consumer perspectives on DD services and barriers to participation
2. To identify areas and subjects to be questioned via the nationwide survey (previously discussed)

The meetings were held in cities which were deemed accessible to an optimum number of each major population grouping. We met in: San Francisco, CA; Los Angeles, CA; Seattle, WA; Phoenix, AZ; Albuquerque, NM; Dallas, TX; New Orleans, LA; Rapid City, SD; Kansas City, MO; Nashville, TN; Atlanta, GA; Chicago, IL; Philadelphia, PA; and Washington, DC.

Initially, our plan was to have parents/consumers and service providers meeting in joint sessions. But after reviewing this plan, it was decided that parents might feel freer if they met as a group in their own session. Thus, we scheduled two sessions per meeting, one for parents/consumers and one for service providers.

During the meetings, the minority participants requested that their comments be shared with service providers. Likewise, service providers, DD Councils and advocacy groups requested to be made aware of those issues raised by parents. Thus, our preliminary report on findings was written to respond to both these requests.

FINDINGS

We were able to categorize the major concerns and issues raised during the meetings into about twenty areas. These concerns center on conditions <u>perceived</u> to exist by minority parents and consumers. Thus, the <u>concerns are not a statement on what we found to exist in the service delivery system for DD</u>, but represent <u>consumer</u> perceptions of conditions and/or situations. These twenty categorized concerns centered around:

1. The developmental disabilities service delivery systems' apparent inability to render services in a comprehensive manner to the family as a unit. Participants stated that they were expected to devote their entire time to the child who is DD. Social workers come into the home and do not see that the minority family often has other survival needs in addition to getting services for their DD child.

   Parents are expected to attend meetings when no supportive services (i.e., babysitting or transportation) are made available. Agencies fail to realize that families suffer an emotional crisis with the birth of a DD child. They need help in accepting this and in dealing with their own self-image.

2. The inability of agencies to reach out into minority communities and inform them about services. Most parents reported that they stumbled upon services, often hearing about a service from another parent or after "knocking on various agency doors". Many report being improperly referred or placed on long waiting lists.

3. The inability of many physicians to diagnose a child's problem and fully explain his/her potential for development in a way to parents which is realistic, yet, not unnecessarily pessimistic. Parents reported incidences of being told to "put the child in an institution", or "leave him in the hospital". Parents also reported that some physicians act as if minority families lack the knowledge to understand their child's condition. Thus, physicians either don't tell them or say "he/she will grow out of it".

4. The lack of informational materials in language which is understandable by both the English and non-English speaking family.

5. Parents also stated that in some instances they felt professionals gave their children an extremely poor prognosis for development because they were minorities.

6. The inflexibility of eligibility requirements, specifically those relating to income. Many single parent families reported an inability to pay for the cost of services in private institutions. They stated that income guidelines do not consider the problems faced by single parents who have other responsibilities.

7. The inability of agencies to focus on the similarities between inaccessibility of services to minority populations and discrimination, resulting in agencies dismissing the concerns of minorities as being the "same as those of the majority".

8. The insensitivity of non-minority staff to the cultural differences of <u>each</u> of the minority populations. Consequently, parents stated staff assumes what is true for the Spanish-speaking is true for the Asian or Black, or they assume all Indians are alike in their beliefs and ceremonial practices.

9. The inability of agencies to recognize, understand and handle parental mistrust. Related to this is the insensitivity parents feel is displayed by some agency receptionists. These are often the first person the parents hear from and if they are turned-off at this point, they (parents) will never call back.

10. The isolation of minorities in rural areas and the greater discrimination often suffered in these areas by minorities.

11. The failure of agencies to involve minorities in decision-making and planning in a meaningful manner, and further, to involve minority service providers in these activities.

12. The burden is placed on the parent to become involved while it should be placed on the agency to make that involvement meaningful.

13. The need for more agencies to recognize parents as a resource for reaching out to those parents who are afraid or ashamed to admit they have a disabled child.

14. The need for many agencies to recognize the value of providing parents the opportunity to have time for themselves away from their disabled child.

15. The need for current service providers to recognize that they cannot be all things to all populations and that in the interest of getting services to minority populations, each minority group might have to plan, design and implement its own service system.

16. The "game playing" agencies undergo when they say they can't find a "qualified minority person" to hire.

17. The value judgement many professionals make equating parent/consumer non-involvement in meetings to mean a lack of concern for their (Parents) child's development. Parents reported that staff assume the parent is uninterested or is a bad parent if he/she doesn't attend meetings.

18. The need for service providers to understand the role of religious and cultural beliefs as they influence the parents use or non-use of services. Parents reported that some agencies don't understand these factors. The reality, parents report, is that many families whether minority or not, have similar beliefs, and further, that the general public has all kinds of myths about the disabled.

19. The lack of continuity in care given minority families who must use public health clinics. Parents reported that they often see a different doctor each time they visit the clinic and consequently, feel as if they (parents) are just another patient. Parents report they resent being pushed from one doctor to another.

20. The need for staff (particularly in the outreach area) who are reflective of the racial, ethnic, and socio-economic class of those being served. The need for agencies to train current staff to be more sensitive to and understanding of minority client's needs.

These 20 concerns are based on our initial analysis of the transcripts of each of the meetings. These are some of the issues as minority parents/consumers perceive them. They are by no means meant to be reflective of all the specific needs of each minority population. For example, the American Indian faces a jurisdictional problem, i.e., between reservation and programs by state or federal governments, in obtaining services, not faced by other minorities.

The Vietnamese American has problems centered around cultural assimilation, as do other Asian Americans who prefer to keep their Asian lifestyles and beliefs. The Spanish-surname Americans who identify themselves as Chicano, Mexican American, Latino, La Raza, etc., each desire input into the system. The same is true of the Black American. His needs are influenced by geographical factors (whether he resides in urban or rural areas) and economic factors (whether he is low or middle income) and cultural factors (his own assessment of what it means to be a Black American). Thus, from each meeting and minority population, we learned different and yet, similar things.

A more detailed presentation will be presented in the final report, which will be issued in October, 1978. Included in that report will also be those issues raised by service providers regarding minority participation. For example, the impact of race vs class prejudice on the service delivery system; lack of coordination in the service system; the definition of and need for "supportive services", etc.

Who were the parents who participated in the meetings? They were Black, Asian (Vietnamese, Japanese, Chinese), Native American Indian (Choctaw, Sioux and Navajo), and Spanish-speaking (Mexican, Puerto Rican) Surname Americans. Now you are probably thinking...Well, we chose parents who were the most critical of the service system. No. We asked agencies to advise their clients of our meetings. We asked the local affiliates of the national organizations to give us names of their minority members and, yes, we got names from the Urban League, Aspira, a Pureto Rican group, etc. But, by and large, our meeting participants were recommended by many of you. So what does this mean? It means that those receiving services are concerned and recognize that their participation impacts on the services their child(ren) receive(s). And, they are concerned about those who are not participating.

CONCLUSION

Relationship of Preliminary Findings to a Model Service Delivery System. It should be clear to you by now that in doing our study, we pre-suppose a special or different need for services by minority persons who are parents of disabled children and/or are themselves disabled.

If it has been easier (and I believe it has) to classify all DD individuals into categorical groups in an effort to make them fit these classified groups rather than to individualize programs to fit the needs of people, it has also happened that differences in needs of the minority DD population have been ignored and little attempt is being made to individualize programs to fit their needs.

Our experience seems to indicate that the DD service system must give recognition to race, cultural and ethnic differences in planning and delivery of services. Services must be developed in regard to race and culture, not "regardless of it".

Thus, we suggest that in planning the model service system you be cognizant of:

1. The cultural beliefs and practices of communities as related to any condition which causes the child to be other than what parents, relatives or friends expected, e.g., How can you successfully treat a family who believes the condition is a punishment and thus, want no interference from outside their home?
2. Family and community structure and the roles and responsibilities as defined therein, e.g., If the grandparent is the "significant other" for the disabled child, the right of that grandparent as relates to the care of the child must be recognized.
3. The total human service system as part of the treatment process, thus, the need to integrate and coordinate services offered under public assistance; SSI, boards of education--special education units, departments of health continuing care units, etc.
4. The need for further discussion on the ramifications of mainstreaming and de-institutionalization by the minority community.
5. The need for guidelines or standards by which minority parents or their representatives can evaluate services received.
6. How agencies often use "lack of motivation" as an excuse for not giving services. We train people to help, show them how to treat others, fund large facilities with huge staffs, yet, the burden is on the client to be motivated to come and get it".

These are only some of the things we need to be aware of in planning services.

Let me close by saying, we cannot plan effectively for people unless we plan with them. This requires true participation.

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REACHING THE LOW-INCOME MENTALLY RETARDED CONSUMER

by

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THE UNSERVED--THE UNDERSERVED

Undoubtedly, ethnic minority, low-income communities throughout the nation consistently continue to be underserved--or unserved--by those resources currently earmaked for the mentally retarded and their families. Exclusionary practices of ommission and commission are manifested through patterns of systematic techniques.

Poor access to service, limited utilization of minority manpower, and minimal minority involvement in decision making exemplify the results of such practices.

Even in those situations where resources for mentally retarded consumers are available, the family with inadequate income and the minority family is apt to have little knowledge of their existence. Moreover, few of the professionals, or the organizations that specifically serve low-income and minority consumers or their communities, are sufficiently aware of the significance of utilizing the resources for the retarded or the ramifications of the condition.

George A. Albee, Professor of Psychology at Case Western Reserve University, states in the article, "Needed--a Revolution in Caring for the Retarded" that since 1963, the federal government has supported research and training at an increasingly unprecedented rate. He further states, "Unfortunately, most of these funds are not being used to help the majority of the retarded...The majority of the retarded need, not medical treatment, but rehabilitative training so that they can use their maximum potential."[1]

In Black Families in White America, Andrew Billingsley declares, "All the major institutions, including, the political, economic, educational, social and others, have systematically excluded the Negro (minority) people in varying degrees from equal participation in the rewards of these institutions. None of them work as effectively in meeting the needs of Negro (minority) families as they do White families."[2]

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[1]Albee, George; "Needed--a Revolution in Caring for the Retarded"; Trans-Action, January-February, 1968.

[2]Billingsley, Andrew; Black Families in White America; Englewood Cliffs, NJ; Prentice-Hall; 1968; pp. 152-186.

In one investigation in Massachusetts, Simon Olshansky studied over 1,000 children whose families received Aid for Dependent Children. He found that 6.7% were mentally retarded. Practically none were getting any significant help. Social service agencies, as is frequently the case, had no workers to do outreach and seek cases that would add to their excessive case loads. But even more official recognition of the problem is documented as evidenced in the 1968 President's Committee on Mental Retardation report: "...our communities health, education and social needs--particularly in low-income areas have become so great, and the resources to meet them so inadequate in their present applications, that fundamental revision of community services has become a critical necessity.[3]

Yet, this same population is credited for contributing 3/4 of the mentally retarded incidences in our society. The late Whitney Young, Jr., at the 1967 Annual Convention of the National Association for Retarded Citizens, commenting on the high incidence of developmental disabilities and mental retardation within the poverty populations, noted: "Because the Negro has suffered generations of discrimination, abuse and neglect, he still lives, by and large, in a life of isolation from the mainstream of society; and also, a life of poverty to an extent which is rarely known by the White world. He, therefore,...pays a heavy price for injustice in the form of a large number of mentally retarded children. These children become retarded, not because they have a bad heredity, but only because the frail and sensitive minds of young creatures cannot withstand the bleakness, the harshness and the cruelty of the life of the poor.[4]

In his landmark study, Hurley established that poverty in America is one of the most significant causes of mental retardation. He goes on to state, "Because of our society's failure to provide a suitable home environment for all of its citizens, the children of the poor (who offer essentially the same beauty and the same human potential as the children of other socio-economic classes) have a much greater chance of becoming prostitutes, juvenile deliquents, criminals, unemployed--or mentally retarded."[5]

Again, the official report of the President's Committee on Mental Retardation for the year, 1968, reveals some well known--nonetheless astonishing data. "Conservative estimates of the incidence of mental retardation in inner-city neighborhoods began at 7%." "A low-income rural or urban family is fifteen times more likely to be diagnosed as retarded than a child from a higher income family."

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[3]President's Committee on Mental Retardation Report: Edge of Change, U.S. Government Printing Office; Washington, DC; 1968.

[4]Young, Whitney; Address to NARC Convention; Portland Oregon; October, 1967.

[5]Hurley, Roger L.; Poverty and Mental Retardation: A Causal Relationship; State of New Jersey, Dept. of Institutions and Agencies; Division of MR: Planning and Implementation Project; Trenton; 1968.

In support of these findings, Wilson Riles, Superintendent of Public Instruction for the State of California, stated publically on several occasions from information gathered in the California annual survey on racial and school population"...the rate of placement of Spanish surname children enrolled in Special Education is about three times higher than for Anglo children. The Negro rate is close to four times higher than the Anglo rate. Children from all minority groups constitute about ¼ of the public school enrollment in the state, but ½ of the Special Education enrollment.

THE CHALLENGE

The ultimate solution to the problem involves an all-out multi-faceted coordinated thrust to rectify the current faults in the system, and to identify and prevent the proliferation of unmet needs of the target consumers in the future. Needless to say, this is a monumental undertaking, which, with appropriate support and commitment of resources, can be accomplished with relative ease. The approach selected should focus on action, implementation strategies, supplemented with provisions for a reasonable amount of relevant studies, research and demonstration. By utilizing existing legislation, funding and available resources and services, combined with a strong affirmative action and equal opportunities thrust, significant gains are obtainable within a relatively short period of time. The essential ingredients, however, are commitment, involvement and appropriate enforcement.

The words of Senator Edward M. Kennedy, although spoken some fifteen years ago, are remarkably applicable to our current dilemma; "I think that we have had enough planning. We have had enough reports. We are organized for action...so now let's have some real action".

SERVING TO ADVANCE REHABILITATION (STAR)

Action indeed! The National Association for Retarded Citizens, as one of the co-sponsors of Project STAR (Serving To Advance Rehabilitation) began to explore resources for expanding its outreach activities. Under STAR, NARC, in coalition with the National Urban League and the Family Services Association of America, conducted model outreach programs through joint sponsorship of each of the organizations' local affiliates in five major cities across the nation. Most of the proven effective features and significant findings of Project STAR were later incorporated into the planning and the establishment of the then proposed program.

Project STAR focused its efforts on identifying, assisting and organizing minority and low-income, mentally retarded consumers and/or parents of mentally retarded persons. The Project was dependent upon parent and consumer involvement. Similarly, utilization of available and existing resources was an essential strategy. Most significantly, STAR was committed to introducing minority and low-income workers into roles of health education, community organization, community and social services paraprofessional specialists. Primarily, STAR successfully demonstrated strategies that effectively enabled minority and low-income clients, consumers, parents, professionals, paraprofessionals, advocates and even representatives of organizations, to enter into (and effectively influence and utilize) the system of resources and planning for the mentally retarded.

The STAR data substantiates the following as major achievements: (1) after participating in the STAR program, the parents reported receiving many new services for their children; (2) many new services were also made available to other members of the families; (3) those who used services for their retarded child prior to STAR, now indicated experiencing better services; (4) knowledge of community services increased with attendance at parent discussion meetings; (5) after participating in STAR, many parents indicated a more favorable appraisal of the retarded child's capabilities; (6) many retarded children were removed from special education classes and placed in regular classes or in special training facilities for the retarded; (7) of the known outcomes of STAR referrals, 74% resulted in the service being delivered to the client; (8) many service agencies surveyed indicated changes in the proportion of low-income and minority-group clients served. The common explanation for the change in client composition was outreach programs such as STAR; (9) fifty-one out of seventy-six service agencies in the survey indicated that they now have residents of the model city neighborhood on their payroll as staff and on their boards as members. Of the 51, 18 were without Model City residents in such roles, the year prior to STAR; (10) 103 persons in all the five STAR cities took positions on local and state boards concerned with mentally retarded. The NARC added minority members, nationwide; and in the five cities, placed 12 on their local boards. The Family Service Association of America added 14 minority board members in the four STAR cities in which they participated.[6]

IMPLICATIONS OF THE STAR FINDINGS

A review of the STAR research findings indicates the viability of the STAR program as a model for (1) increasing the involvement of low-income families as consumers in the local service delivery systems for the mentally retarded; and (2) promoting the participation of low-income clients in program formulation and decision-making in the existing service system.

THE STOP ORGANIZATION OUTREACH MODEL

by

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Prior to the presentation of the STOP Organization's Outreach Model, I feel that the role of the STOP Organization must be first fully understood. Time limitations suggest that I purposely omit the quantum documentation of the existence of poverty in the STOP Organization service area, i.e., Virginia Planning District Twenty (20) which includes the Cities of Norfolk, Portsmouth, Chesapeake, Virginia Beach, Suffolk, Franklin and the Counties of Isle of Wight and Southampton. Full documentation is, of course, available.

The principal purpose of the STOP Organization, as is the case of most community action agencies, is to stimulate a better concentrated focus of all local, state, federal and private resources. The main goal is to enable poor and impoverished individuals and their families in urban, rural communities to obtain the necessary skills, knowledge, motivation and competence in these areas to become more self-sufficient and self-sustaining.

It is our belief that the escape from poverty, on the one hand, is intimately associated with an ability to demonstrate social competence. These necessary competencies, in most basic terms, fall in the areas of the psycho/social, the educational, the political and the economic. The preceeding statement may seem to suggest that no other "x" factors exist which may realistically and/or potentially block an individual's or a family's escape from poverty. We are, fortunately, not so naive.

Within the identified political context as well as in our intensive commitment to serve the "community-as-the-client-", on the other hand, we aggressively attack such other "x" factors which effectively serve to block an individual's or a family's escape from poverty. In other words, we do aggressively focus on racial discrimination, political lack of awareness, and total interpersonal family development, (as well as other related "x" factors).

A few words, at this point, appear indicated about the STOP Organization's "Total Family Concept". Knowledge and understanding of this concept is necessary if you are to understand our outreach model and service delivery systems. As a practicing family counselor, I am certainly appreciative of the "importance of family". The family unit is most basic to society. Strength in these units is necessary if we are to achieve our agency mission. Inherent in the human condition is survival in groups. In order for an infant to survive, there exists a need for mothering in terms of feeding, protection, and socialization.

Industrialization has made it necessary for man to develop specialized skills as well as the capacity to adapt. The family, then, must provide for the psycho/social protection of its members while at the same time seeking accommodation and transmission of culture.

The impact of industrialization has been forceful. Many support systems previously provided by the family have now been intruded upon by industrial as well as social welfare systems. In many instances, this impact has proven traumatic.

In a similar fashion, as effective family counseling service provision, the STOP Organization does not just examine the individual who presents himself or is referred, but seeks to examine all that represents his family system. His needs as well as those of his family are thoroughly assessed. It is our belief that singular intervention will not lend itself to the full realization of those competencies needed in order to become upwardly mobile. Only through "Total Family Intervention" will this goal be achieved.

The STOP Organization's Total Family Concept operationally seeks to assess needed service both within and without its capacity to provide these services. An example might now provide for clarity. A client referred for employment training is not assessed only in terms of his employment skill level or training needs, but also in terms of the educational needs of his children, the housing needs of his family, as well as the nutritional needs of his family. This individual may also need advocacy assistance in his interaction with other public and private agencies to secure needed services.

The STOP Organization maintains two (2) broad program categories of service assistance. These services include Manpower-Training and Technical Assistance and Social and Community Services. The manpower services aggressively address those skill training and experience needs of our consumers of service. The training is, of course, skewed in the direction of obtaining those necessary employment competencies needed by clients to enhance their employability and, hopefully, subsequent economic self-sufficiency. Programs included in this service area are CETA Training and Employment Placement, which includes both the Public Sector Careers and Work Experience Programs. Specialized areas of training such as the LPN Training Program are also included. The program packages address all aspects of needed competence from the employment application process, to obtaining needed technical skills, to positive work and interpersonal attitudinal considerations. Personal and family money management is also given extensive program attention.

Social and Community Services, as a separate, but intimate associate of Manpower Services, are provided by the STOP Organization. Program areas of this division include the following:

1. Volunteer Services
2. Community Food and Nutritional Services
3. Senior Citizens Services
4. Housing Services
5. Weatherization Services, including Emergency Fuel Assistance
6. Water and Sewer Services
7. Neighborhood Development

8. The Head Start Program
9. Youth Services
10. Special Community Programs including a lead based paint removal project and a STOP/Mobility on Wheels Program designed to develop an access guide for several cities within the Planning District.

All of the above mentioned programs and their services interface and fit into the assessment process and form the STOP Organization's "Total Family Concept". Many clients and their families are recipients of a majority of these services.

Now that you have some beginning understanding of the STOP Organization's purposes, goal and service provisions, as well as our Total Family Concept, it is now appropriate to discuss its outreach model and service delivery mechanisms.

The STOP Organization as a community service agency has created a marriage of the three (3) basic approaches in providing community services. Jack Rothman, in his article on Models of Community Organization Practice, identified the following as basic practice models:

A. Locality Development - This model presupposes that community change may be pursued optimally through broad participation of a wide spectrum of people at the local community level in goal determination and action.

B. Social Planning - Emphasizes a technical process of problem solving with regard to social problems of substance such as delinquency, housing and mental health. Rational, deliberately planned, and controled change has a central place in this model based on the assumption that change in a complex industrial environment requires expert planners.

C. Social Action - This model presupposes a disadvantaged segment of the population that needs to be organized in order to make adequate demands on the larger community for increased resources or treatment more in accordance with social justice of democracy.

The marriage of the three (3) basic models has effectively enhanced STOP's ability to serve its consumers of service. The restrictive limitations of the utilization of just one model do not exist. Historically, the service drift has been from more of the social action model to the locality development and social planning models.

At the very heart of the STOP Organization planning, outreach, and service delivery processes is citizen participation. STOP's Board structure epitimizes its commitment to citizen involvement. The historical and present Board composition includes the following three (3) major groupings: Group A of the Board of Directors, Groups B of the Board of Directors and Group C of the Board of Directors

In addition to the above described composition of the STOP Organization Board of Directors, there exist ten (10) mini-Advisory Boards serving each identified area scattered throughout Virginia Planning District Twenty (20). These mini-Advisory Boards are composed of elected community representatives from their respective service areas. Each mini-Advisory Board has ten (10) members. Nine (9) of the members

of the mini-Advisory Board are elected while one member is appointed to serve by the STOP Organization Head Start Parent Policy Council. One member from each of the ten (10) mini-Advisory Boards is selected by his particular Board to serve as a full member of the main Board of Directors for the STOP Organization. It should be clearly understood now that STOP's consumer population maintains a full and real voice in the STOP Organization policy making process.

An analysis of recent trends in social agency systems seems to suggest a drift from a maximum commitment to client involvement. The STOP Organization is steadfast in its commitment. One of our most successful programs, Head Start, provides an excellent example of the benefits of consumer involvement. In Head Start, the parents have a real voice in almost all aspects of program matters including the appointment of aides, teachers, as well as the program director. In a recent interview with the Chairman of the Head Start Parent Policy Council, it was reported by the Chairman that, outside of the education of the children, parents were most appreciative of their real voice in program matters. They made sharp contrast to their interactions with other public and private educational institutions. In STOP's twelve (12) year history no significant conflicts have been noted that have gone without positive resolution.

The STOP Organization maintains physical decentralization through its network of ten (10) Neighborhood Outreach Centers. The single most important aspect of this network is that real or potential clients need only to touch base with one of these centers to have all services that represent the STOP Organization at their disposal. While it is true that all services are not available in the neighborhood centers, they can, however, be mobilized from these centers. Many services are indeed available right there. For services not available on site, transportation to these needed services is available by staff or volunteers.

STOP's concept to outreach goes much deeper than just availability in the neighborhood. We maintain a commitment to move out of the outreach centers and into the community that we serve. It is quite possible to maintain an "ivory tower" posture while being physically located in the neighborhood. This is a situation that STOP has sought to avoid throughout its twelve (12) year history. In order to remain in touch "with-the-pulse-of-the-communtiy", in other words, we must move out of the centers and move into the community. This posture is most important even though we have neighborhood representatives on our main Board as well as our mini Boards in that the "true pulse" of the community can only be experienced through true community interaction.

Residents have their own opinions about what neighborhood problems are and which ones are important. Our active community interaction facilitates our sensitivity in this respect. On occasion, neighborhood persons may not idenfity those problems which are most detrimental to their neighborhood. In such instances, our participation enables them to expand the parameters of their community sight and, thusly, creates a greater feeling of dual positive regard. In turn, residents will be more supportive of a program whose activities include those which respond to their immediate needs and desires.

The STOP Organization's concept of outreach examines the identified needs in terms of cause and effect/solutions and services. Preventive assistance maintains an extremely high priority in our provision of services. Our "Total Family Concept", mentioned earlier in this presentation, maintains significant preventive dimensions. If "Total Family Services" are provided, individual family members will have a head start against the forces and circumstances that make and keep people poor. Prevention, therefore, must be an integral part of any outreach effort.

Like many similar outreach program efforts, the true realization of our outreach abilities is restricted by resource limitations. This real world circumstances, however, is no cause for feelings of hopeless despair. Creative programming, as well as the sophisticated mobilization and utilization of volunteer and other community resources, can significantly augment outreach service provisions. These other community resources include churches, community business persons and community social and civic organizations.

An effective outreach model is always one that does not breed dependency on its continued existence. The STOP Organization's Outreach efforts are always preparing neighborhood persons for our departure. If our efforts are successful, when and if this departure point presents itself, the community will be in a better position to be self sustaining, as will its membership. Outreach efforts must then be always assisting residents to undertake independent actions to improve their own lives.

The STOP Organization's Outreach Model maintains an equal focus on "process" as well as "task" goals. The process goals in our model are directed toward the community's ability to function over a period of time. We seek to enable community strength to become a self-sustaining community problem-solving entity. Community leadership development is one such process goal. Our task goals include our program efforts that are directed toward the elimination of specific problem areas such as housing and youth delinquency. Decentralization of many of our services facilitates the achievement of these ends in that we are "where-the-action-is".

Our model stresses empathic understanding and knowledge of the community. The outreach worker, however, need not necessarily, be from the particular neighborhood or an impoverished background in order to develop these capacities. The outreach worker must, however, examine the community scientifically to properly chart an effective problem solving path that will enhance service delivery. The mission of our outreach model, then, is directed toward community enabling capacities. Attempts are made to engage all segments in the community in common problem solving.

Finally, the STOP Organization's Outreach Model is representative of our belief in "people-helping-people". We seek to enhance the unique value of people and move them toward greater social sensitivity, responsibility and self sufficiency.

THE NORFOLK STATE COLLEGE MODEL FOR SERVICE DELIVERY TO MINORITY DISADVANTAGED POPULATIONS

by

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Norfolk State College is a multi-purposed, multi-cultured, urban institution of Higher Learning. It has been developed and nurtured by its community, a growing metropolitan complex of cities. It has a continued history of concerns and identification with urban problems, and has developed programs and strengths around this interest. The College has been and will continue to be especially engrossed with the improvement of the human environment and the development of human resources by providing high quality education for students with a wide variety of backgrounds. We strive to prepare students for competitive excellence in present and emerging career fields.

The College has grown from 80 students in 1935 to over 7,000 in 1977, from a dependent 2-year institution to a graduate degree-granting institution, with alumni scattered around the world as active, productive participating citizens. Among our nearly 900 graduates last June, were 35 young men and women commissioned officers in the Armed Forces of the United States. Our faculty is cosmopolitan; educated, and trained in the best universities of the world; bringing to students varied experiences, economical, cultural, social and ethnic.

The College is regional accreditated by the Southern Association of Colleges and Schools. Its programs have professional accreditation from such agencies as the American Dietetics Association, National Association of Schools of Music, Council of Social Work Education, American Speech and Hearing Association, National Council for Accreditation of Teacher Education, etc.

The College has what is generally spoken of as an open-door admission policy, accepting students with a wide variety of backgrounds and providing individual, selective curricula to meet their needs and aspirations. There are appropriately designed curriculum programs that are multidimensional in scope and outreach, taught by uniquely prepared teachers. One program that we call the "Transitional-Year Program," where communication skills are explicated has reported that on the average, students gain three reading grade levels for each semester of participation. There are other programs where remarkable results are reported. The Trio Program - Special Services, Talent Search, and Upward Bound; the Cooperative Education Program and Continuing Education Program are but a few of the supportive services afforded Norfolk State College students.

The Human Resources Laboratory and the Gerontology Center, although located on the campus are almost totally community centered and people oriented; students with their instructors hold workshops, seminars, conferences, surveys, and studies for community agencies and individuals in delivering services to the public.

Besides a Liberal Arts Component, the College has divisions of Business, Technology, Nursing, Home Economics, Education, and a Professional School of Social Work.

The Teacher Education Division's work is primarily community based. This division, following a needs assessment, developed a set of teaching competencies that they believed a teacher should have to successfully perform in classrooms generally found in the inner city. Programs were then formulated on the premise that having identified and analyzed the behavioral needs for the teaching role, one can then design a program of instruction to produce skills and behaviors needed. Then, the kind of changes in students that one believes society embraces were identified and the kind of teaching performance most likely to influence these changes were adopted.

A number of funded projects have been used to enhance and improve teacher education programs. An EPDA project, designed to sensitize regular classroom teachers to the special needs of children and youths was conducted in Tidewater school systems from 1969-1975. During this period, 260 principals, teachers, and teacher aides participated in experiences designed to increase the competencies of regular classroom teachers to deal effectively with children with exceptionalities in the regular classroom. The Teacher Corp Project, in its 12th cycle at Norfolk State College, 1971-present, is designed to help preservice teacher interns and cooperating teachers develop skills to deal effectively with learning and behavior problems in the regular classroom. A third project, Early Childhood Education for the Handicapped (ECEH), was designed to lessen the motor, mental, and emotional effects of a combination of mental retardation, secondary deficits of hearing, vision, speech, and lack of stimulation on young, disadvantaged handicapped children.

These and other similar programs, all having a component on parental instruction and assistance, have enabled the education division to improve its teacher education programs, while providing services, knowledge, and experiences to the local and extended communities.

This model of community concern, and community involvement has sensitized and helped develop a spirit of cooperation among students, parents, teachers, and other community workers to assist in the process of identifying factors which restrict the development of human potential among minority groups. It has helped the College to effectively train prospective and in-service teachers how to provide for the needs of handicapped children in the regular classroom, and it has provided appropriate programs to assist agencies in the support and training of parents how to become active partners in the encouragement and development of their children.

GENETICS IN THE TIDEWATER AREA

by

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Cytogenetics is the study of visible chromosomal alterations associated with human disease. Cytogenetic analysis is useful for the following diagnostic situations:

1. detection of congenital birth defects in infants
2. genetic counseling
3. sexual problems
   a. newborn intersex
   b. primary amenorrhea
   c. sexual infantilism
   d. sterility
   e. premature menopause
4. prenatal diagnosis
5. evaluation of abortus material
6. medicolegal studies
7. hematological disorders

Of the twenty-two pairs of autosomes, only four autosomes have been affected by structural or numerical abnormalities with sufficient frequency that well-defined syndromes have been recognized. The common autosomal syndromes are Down's Syndrome, Patau's Syndrome, Edward's Syndrome, and cri-du-chat Syndrome. Other autosomal defects are now being reported and will probably be classified as syndromes.

The sex chromosomes of man are called X and the Y chromosomes. Genetic sex in humans is determined by the presence of an homologous (XX) sex chromosome pair in females and a non-homologous (XY) sex chromosome pair in males. The genetic sex of an individual is determined by the Y chromosome. If the Y is present, the individual is a genetic male; if the Y chromosome is not present, the individual is a genetic female. An amazing array of aneuploidies, mosaics and structural defects affect the sex chromosomes. The sex chromosome defects produce gonadal dysfunction and genital anomalies of varying severity. Some patients are completely asymptomatic and have completely normal sexual function. The most advanced of the sex chromosome defects, the sex chromosome monosomies, produce the agonadal pattern and the patients appear to be hypoplastic females. Intermediate defects in which varying degrees of male and female differentiation are intermixed may be the most difficult to treat.

Sex Chromosome Defects

1. Clinical Intersex
   a. 45,XO/46,XY
   b. Testicular Feminization

2. Gonadal Dysfunction in Apparent Females
   a. Turner's Syndrome
   b. Chromatin Positive Gonadal Dysgenesis
   c. Testicular Feminization
3. Gonadal Dysfunction in Males
   a. 46,XX Males
   b. Klinefelter's Syndrome
   c. Mosaic Klinefelter's Syndromes
4. Structural Defects of Sex Chromosomes

Cytogenetic studies can be performed on peripheral blood, amniotic fluid, bone marrow, and solid tissue samples. Cytogenetics is an area of medicine that is becoming one of the most helpful diagnostic procedures for the answer to certain diseases that in the past went undiagnosed.

GENETICS OR ENVIRONMENT:

BLACK INTELLIGENCE AND ATTAINING OUR POTENTIAL

by

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Intelligence has been defined in many different ways and writers on the topic are still in wide disagreement. Originally the term was used synonymously with intellect, which was defined as the faculty or capacity of knowing. However, present day concepts of intelligence are broader, concerned more with adaptive human behavior and sometimes cover so-called non-intellective factors of intelligence. Most definitions of intelligence emphasize certain capacities as basic to general intelligence. The three most often mentioned are the ability to learn, the ability to reason and the ability to profit from experience. The ability to solve problems is a fourth capacity frequently mentioned. When we examine the tools which are used to measure intelligence, we find that not only these, but other abilities as well are utilized. The current view is that general intelligence involves not only learning, adapting, reasoning and problem solving, but also a variety of capacities which in one way or another enable the individual to cope effectively with his environment. This is why I will talk today on "Genetics or Environment: Black Intelligence and Attaining Our Potential".

Dr. Arthur Jensen, Professor of Educational Psychology at the University of California at Berkeley, has published his argument of Black genetic inferiority. His argument consists essentially of an elaboration on two given facts, a causative explanation and a programmatic conclusion. Fact one is that Blacks perform on the average, more poorly than Whites on standard I.Q. tests. Fact two is that special programs of compensatory education so far tried have not had much success in removing this difference. His causative explanation for these facts is that I.Q. is 'highly' heritable, with most of the variations among individuals arising from genetic, rather than environmental sources. His programmatic conclusion is that there is no use in trying to remove the difference in I.Q. by education, since it arises chiefly from genetic causes and that the best thing that can be done for Black children is to capitalize in those skills for which they are 'biologically' adapted.

Dr. William Shockley, Nobel Prize winning physicist of Stanford University, shares Jensen's views concerning genetic heredity. At this point, I must interject that Dr. Shockley is attempting to transfer his credibility from the area of physics to that of genetics because he received the Nobel Prize for his part in the discovery of the transistor, not in sociology nor genetics. His theory is that the more White genes a Black has, the more intelligent he is. Specifically, he

claims that the United States Black population has lost six I.Q. points relative to Whites since 1918 because of the porgressive reduction in its Caucasian gene component. It is his belief that the portion of the Black population suffering mental retardation for genetic reasons may double in about 20 years. His solution to the problem is twofold. He proposes that there should be payment of Federal cash to intellectually 'substandard' Blacks who agree not to have children, and that there should be establishment of special educational and social programs geared to 'substandard' individuals.

The two given theories totally emphasize suspected correlations that may occur between heredity and I.Q. Brushed aside or totally ignored was the environmental impact on intelligence and intelligence testing. Jensen, himself, states that I.Q. testing was developed in a western industrialized society specifically as a measure of success in that society by the generally accepted criteria. This in itself, to me, is a strong argument against I.Q. testing for so-called deprived children because these children have developed in a subculture and their subculture does not prepare them for such tests. A good example comes from the television show Good Times. In one particular episode, Michael stated that a friend of his did not do well on an I.Q. test because it was biased against him. One example on the test asked for the matching of "cup and...". The selection included, table, saucer, chair and knife. The friend had chosen table, because where he lived there were no saucers. Cups went on the table, and to the friend, this was the correct combination.

The above is one example of how one's social and cultural environment plays a great importance on how one perceives the world. Another factor, one of the most obvious environmental factors affecting intelligence in that of nutrition.

Dr. Myron Winick, as scientific researcher who has published numerous articles and presented many papers on nutrition and mental development, has stated that the last trimester of pregnancy through the first 6 months to 1 year of life is the most critical period in a human being's development. This is the period when brain growth is most rapid and, thus, most vunerable to interference by undernutrition. After this period of infancy, the brain never gets another chance to "catch-up" in its growth or potential. Dr. Winick has demonstrated that cell division stops at approximately the same age in both undernourished and well nourished children. However, malnutrition has a direct effect on the way the brain grows. If a newborn is seriously undernourished during the first 6 months after birth, cell division is slowed by as much as 20 percent. A seriously deprived fetus may have 20 percent fewer brain cells than normal. Thus, the infant who has been malnourished both "in utero" and after birth could have a brain as much as 40 percent smaller than its potential. These facts have tragic implications for the determination of intelligence in different socio-economic and ethnic groups.

However, there are also many positive implications for those who care for mothers-to-be and then their infants. To me, it shows that there is an overwhelming need for community prenatal and newborn

clinics. These clinics should be in all lower-socio-economic neighborhoods, especially in inner-city areas. These clinics need to become a part of the neighborhood. The clinics should be established on a one to one basis. For example, Richmond has set up community clinics. Follow-up statistics have shown that these clinics are used more by the community than are central clinics. There are fewer no-shows and the health care workers are treated as friends.

The proposed clinics would teach the mother-to-be, who are on limited incomes, to select adequate foods to eat during pregnancy, foods that are both nutritous and economical to the mothers-to-be. They should be taught to read labels on foods and to understand what nutrients are necessary for them and their babies. The clinics would teach the mothers of newborn children which foods are needed by the infants. Suggest breast feeding for the first few months, if possible, for the mothers. Teach the mothers how to make their own baby foods from what foods they have already at home. The clinic could even have a blender for the mothers to use if they don't have one themselves.

The importance of these nutrition clinics cannot be under-emphasized. They won't make our next generation a generation of I.Q. geniuses, but each and every child would be able to attain his intellectual potential. (Cultivating this potential is another topic, another barrier to be overcome.)

To get these clinics, we will have to fight hard for them. We will have to band together into community groups. We have to make city hall hear us 'en masse', as well as to attempt to provide for ourselves. We have to have professionals volunteer their time. There has to be a community effort to establish a place for housing the clinics.

We have to provide for the future of our unborn children, for if we don't, who will?

THE ROLE OF THE PREDOMINANTLY BLACK COLLEGE IN THE EDUCATIONAL PROCESS

by

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Black colleges in America rose out of the ashes of slavery; they stand as monuments to the history of the education of Black people in this country. Like all other educational efforts for Black Americans, these institutions were born out of economic expediency and social bigotry and nurtured by prejudice and discrimination. Emerging from the crucible of misdirected efforts of hungry, inhuman slaveowners, our education--at all levels--has been tried against the odds of survival and our colleges have continued to be forged in furnaces of struggle for the education of Black citizens. The role of the Black college, then, is intrinsically interwoven with the history of all other aspects of Black education in this country.

A quick glimpse at some phases of the history of Black Americans will reveal a pattern of events that has pervaded practically every phase of our education.

Historians tell us that Africans brought to this country were educated in servility. Slave breakers set out--through well-planned, systematic and psychological methods--to destroy the slaves' self respect and to teach them to obey without question. The trusted slaves were pressed into the service of teaching other slaves the bare essentials of English--just enough for them to understand commands and prohibitions and just the skills they needed in order to work the fields.

We are also told that slave owners felt that some experience with religion would be good: This would help to shape the character of the slaves and it would likewise make them more obedient and humble. Therefore, just enough instruction in reading was commonly provided then, it was hoped, so they could study the Bible.

However, we know that in this method of control over human beings, that there was a grave miscalculation. You cannot cut off an appetite, a thirst, a desire, or an ambition as you would close a spigot to hold back the water.

Controllers of the destiny of these people did not recognize at first, yet discovered later, that if you can read English, you can read the Bible but you can also read letters and law; you can read freedom tracts and escape routes. The slaves soon learned

that the Bible teaches tolerance and humility, but it also teaches humaneness and the brotherhood of all men. And when the slave owners discovered it was risky to teach the oppressed to read, this discovery was a bit too late: Their technique was like that of using an insecticide which is excellent for killing the worm but it inadvertently kills the flower, too.

Very early in the history of our education, then, we saw two patterns develop: One was the influence of religion as evidenced in the fact that several Black colleges were founded by religious denominations. And, two, there is an emphasis on the practical. An early observation revealed, for example, that the slave owner taught some slaves to perform any task on the plantation from construction trades to millinery to steam fitting to veterinary services. This made them valuable commodities, not only because they could be hired out, but also, they brought higher prices when sold. This emphasis on trades has continued--with early beginnings, as we know, in such institutions as Tuskegee and Hampton Institute.

The role of the predominantly Black college is implicit, therefore, in its history.

How fortunate it is that from these days under the guise of worship, some of our ancestors tasted the sweetness of knowledge and had the wisdom to learn to read and write! And since that day, the pursuit of education has been deemed an important route to freedom and equal opportunity for Black people. Indeed, this is the theme of Black survival. And despite those who suggest that education doesn't make a great deal of difference, to most Black Americans, access to education is the great equalizer--the key to upward mobility.

It is fortunate, therefore, that--capitalizing on the gimmicks used by slave owners--churches, missionaries and sympathetic philanthropists, along with Blacks, themselves, established numbers of private educational institutions to educate Black citizens. It is also fortunate that the swell of private opinion and unrestrained efforts eventually burst into enough public action in the half century after the Civil War to cause the 17 Southern and border states, joined with Ohio, to create a number of public colleges for Negroes. It is these public and private institutions that are the center of our discussion tonight.

I don't believe that it is necessary for me at this time to probe into the struggles that the political, social and financial climate of America forced upon these institutions: These facts are so well known to us all. In fact, Dr. Dewitt Proctor, a former Black College President once suggested that the very fact that the predominantly Black colleges exist at all or had to be invented in the first place is an awful commentary on American culture.

The role of Black colleges in American society is implicit also in the documented achievements of their graduates. These institutions have a record of taking many students--who pour in from rural areas, from small towns, from big city ghettos--who more often than not are poor and poorly prepared, and educate them into a society that is often hostile or leastwise indifferent. One educator, calling the Black college a place for the metamorphosis of Black youth says. "These students change from fearful wandering illiterates to confident secure seekers after truth; they come in from bean fields and leave as social workers, teachers and technicians; they come in raw talent, untapped and undiscovered and leave as opera singers, professional athletes, medical doctors, engineers and accountants. Without these schools, he concludes, the masses of Black folk would still be without medical or dental services, social workers, or teachers who know them; and there would be no Black middle class."

The records are replete with information which point to outstanding contributions to American life made by Black institutions. As reported by Elias Blake, Jr., formerly President of the Institute for Services to Education and presently President of Clark University, Atlanta, the Institute conducted a study in 1969-70 which documented this assertion:

1. Of the nine Black Ambassadors, at that time--four graduated from Black colleges and three others had been affiliated with such colleges before they became ambassadors.
2. Seventy-five percent of the Black army officers commissioned each year were graduated from Black colleges.
3. In 1960-70 about 75 percent of the 5,600 Black active duty officers were graduates from Black colleges.
4. In the Executive Branch of Government, the study identified as graduates of Black colleges, 64 percent out of a sample of 80 Blacks who were paid above GS-14. This group included Cabinet Officers and the Special Assistants.
5. In the Congress of the United States, specifically the Congressional Black Caucus, 8 of 9 graduated from Black colleges. It might be added that the only Black U.S. Senator is a Black college graduate.
6. In a national survey, of 110 out of 166 Black State Senators and Representatives, it was found that 64 percent of them attended Black colleges; 83 percent graduated from Black institutions in the deep South; 100 percent of them who went to Black colleges did, indeed, graduate.
7. Out of 1,000 Black Ph.D.'s, about 75 percent were graduated from Black colleges.
8. And numerically, it was discovered that in a ten-year period, about 230,000 Baccalaureate degrees had come out of predominantly Black colleges.

These colleges--born in post war poverty, funded on anemic budgets, often systematically understaffed for decades, operating near impossible odds, and little recognized for more than a burden on the taxpayer--for 100 years, have made it possible for generations of Black minds to serve as leaders throughout the world. Therefore, they have become one of the nation's great assets, a great national resource.

Is it because the attorneys who argued the 1954 desegregation case were graduates of Black colleges, that they were better equipped to argue the case for desegregation? Benjamin E. Mays thinks so. He says, "The case designed to dethrone this god, segregation, was not developed in the law schools of the Universities of Chicago, Columbia, Harvard, or Yale, but the Law School of Howard University. It is not by accident that a university born of interracial world view would take leadership in this field rather than the big ten universities which at that time had no concern in abolishing segregation. It is conceivable that if there had been no Howard University, we would not have had the May 17, 1954 decision of the United States declaring segregation in the public schools unconstitutional." To quote Dr. Mays further, "How strange, how ironic, that this nation, conceived in liberty and dedicated to the proposition that all men are created equal had to wait 178 years for the descendants of enslaved persons to help it implement the Declaration of Independence. Surely, God moves in a mysterious way."

Likewise, it is not accidental that Norfolk State College was chosen as a site for this special and important seminar on the national concern for mental retardation among minority disadvantaged populations. One of the basic functions of the predominantly Black college is to serve as a site for probing and research into problems related to minority people, or to serve as a resource center where such a conference as this can be held. The Black college is a natural for this type of activity: It has the staff with understanding, experience and skill to deal with minority people's problems. It houses collections of materials in forms of books and journals that treat the various aspects of these problems. It has access to the subjects and the specimen in their natural surroundings. In most cases, these institutions have already initiated research or collected data or conducted programs which are relevant to the problems that are identified. Mr. Fred Krause, Executive Director of the President's Commission on Mental Retardation recognized this capability evidently, as he is reported to have said to a local newspaperman that Norfolk State College has been "involved in the field for some time and we are interested in how they are preparing students to work with the mentally handicapped."

My point is this: An important role of the Black college is to take the lead in providing information and in training leaders to deal with problems that are relevant to the lives of all minority peoples.

Throughout the more than a century that Black institutions have served this nation, there has been a concerted effort by some not only to discredit these institutions, but also, to prove that Black students are innately inferior. That is to say, that these critics have consistently sought to convince America that Blacks lacked the innate ability and capacity to learn on the higher level. They have attempted to prove that Black colleges must of necessity, therefore, play out a travesty of the mission and practices of higher education. One of the roles of the predominantly Black college has been, therefore, to continually establish itself and its credibility and at the same time, help its students maintain their dignity and have a respect for their noble heritage.

The practice of condemning the entire race of Blacks began in the slavery period, no doubt, because of the vested interest of those who owned slaves. The fathers of the constitution, George Washington, Patrick Henry and others owned slaves. The majority of the members of the U.S. Supreme Court at the time of the Dred Scott decision were owners of enslaved persons. College Presidents and Professors defended the system of slavery.

Critics have said that Blacks have limited capacities to learn and in some cases, they have attempted to produce statistics to prove it. The fact that the Black college has reversed the statistics and proved these allegations totally false, is justification enough for its existence.

It is incumbent upon Black colleges to acquaint students with their roots, to celebrate the survival of Blacks in the culture, to clear the record about their contributions and to keep the truth alive. This does not mean that we should not study Alexander the Great... Charlemange...Louis XIV...Desraeli...Thomas Jefferson...or Winston Churchill. This is a body of knowledge that everybody in the Western Hemisphere should have. It does mean, however, that we should make every intelligent literate person aware of the Black experience in America. Such a subject is certainly as worthy an academic pursuit as the Boston Tea Party or the Torture of Witches in Colonial New England.

I say that the role of the Black college in American education is evolutionary and unending. While many of its fights against racism will no longer be fought in the courts, the fight for its survival and viability will rest in programs and services and the ability to garner the financial resources to support them. The Black colleges will be challenged to create and design programs which will close the gap between the college and university men and the dropouts and the unskilled; those who live in ghettos and slums; those who are poorly housed, ill clad, living on substandard salaries or no salaries at all. They will be challenged to take the gown to town and to the slums, and bring the town and slums to the campus. By precept and example, they must espouse the famous dictum of John Donne--No man is an island entirely of itself; every man is a piece of the continent, a part of the main. Eugene Debs has said, "As long as there is a lower class, I am in it. As long as there is a man in jail, I am not free--no man should set himself apart from mankind."

Of all the missions a college may embrace, I think none is more noble than this: To make known that which is truth, to cultivate a love for beauty, and to serve the people. The Black college cannot afford to do less.

SUMMARIZING COMMENTS AT THE FIFTH GENERAL SESSION OF THE MULTICULTURAL SEMINAR ON MENTAL RETARDATION

"The Role of American Colleges and Universities with a Black Heritage"

by

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Mr. Krause, ladies and gentlemen, the speakers who have already commented upon President Harrison B. Wilson's eloquent address have each made excellent amplifications. I must attempt some observations. Dr. Wilson made at least ten important points, the first of which is that Black colleges arose out of the ashes of slavery to make a distinctive contribution to the education of disadvantaged Americans, including a very large number of handicapped persons. I would like to amend that observation to say that Black colleges arose during the period of slavery and had a major second stage of development after 1865.

It should be a matter of special historical pride to you that founders of several of the earliest colleges were from right here in the Maryland-Virginia area. One of the most dramatic and profound stories during the period of slavery is of a slave from the District of Columbia who founded the first institution of vocational education in Canada. His name was the Reverend Josiah Henson. Because of our ignorance of the true dimensions of his life and of the great book which used his life and work as model for protest against the institution of slavery, we stigmatize his memory and place in history by a serious misuse of the phrase "Uncle Tom".

That great man made a significant contribution by taking his family and fourteen others in his charge from Washington to Kentucky and thence to Canada where he founded a community which eventually received over two hundred slave families brought to him and by him on the Underground Railroad. As early as 1839, he organized the British American Institute in Dresden which is recognized as the first vocational school in Canada. He founded also the Bethel M.E. Church in Chatham which had a definitive role in later American events, because it was in his community and in that church that the historic Chatham Conventions of 1858 and 1859 were held as a prelude to the Harper's Ferry Raid of 1859.

John Brown came across from Kansas to participate in those conventions where a constitution was designed with a commitment to establish a new territory in the United States where everyone would be free in the full meaning of the Declaration of Independence. In that age and context, such a conference was as ideational and pioneering as this meeting which you are having here on the question of the inalienable rights of the mentally handicapped and the responsibilities of the government to assure that those rights are protected and respected. Out of those conferences

at Chatham and a final meeting in Detroit came the final decision to support with volunteers the demonstration led by John Brown at Harper's Ferry. It is of equal interest that Storer College in Harper's Ferry was the focal point of this event and even the subsequent organization of the National Association for the Advancement of Colored People.

Norfolk has its own special uniqueness with respect to significant points of historicity, for it was right here in the Norfolk harbor that John Earl of Dunmore, British commander, issued a proclamation of emancipation for American slaves on November 7, 1775 in the middle of the Revolutionary War. Ironically, George Washington, American commander, had de-enlisted and de-commissioned Negro soldiers and officers from the colonial army. It was this action in Norfolk harbor and the success of British recruitment which forced the colonists to reconsider and re-enlist Black soldiers and officers in the Revolutionary Army.

The second important point made by President Wilson is that the education of American Negroes has been forged in the crucibles of both racial segregation and dehumanizing racial prejudice. Yet it has survived and made a most fundamental contribution to enhancing the quality of American life, especially that of disadvantaged persons. The Black colleges are deeply and intrinsically interwoven not only with the history and circumstances of Black people, but with the nation itself. They are inseparably linked to both the history and the destiny of all other Americans.

A third important point which Dr. Wilson made comes as a reminder that once an appetite, a thirst, an ambition for learning and advancement is stimulated; it can be frustrated, misdirected or distorted, but it cannot be permanently arrested. He demonstated this point in his own life and in his recall of what is now generally termed the "black experience". He reminded us that the pursuit of knowledge has been and should continue to be veiwed as the great equalizer and the key to upward mobility by all disadvantaged persons. This includes the Helen Kellers and the Wilma Rudolphs of our time who overcame the twin disadvantages of poverty and physical handicaps. The Black College is and has been a key instrument of such mobility for persons from all circumstances of life.

The numbers of persons who came to Black colleges as indigents and left them as highly motivated professionals is legion. The records of the United States is replete with their accomplishments, even though we continually diminish the knowledge of the importance of Black institutions to those persons and to their accomplishments. These colleges and universities are, indeed, a great national resource.

With so much in the unspoken history and experience of Black institutions and their leaders, they unquestionably bring a special brand of wisdom to the field of education for the handicapped and to the development of national consciousness of the need for special community programs. Dr. Wilson further reminded us that we must place all of this in the simple context of understanding that the phrase "all men are created equal and are endowed with certain unalienable rights" means specifically that retarded people are citizens of our society having all of the rights and entitled to all of the privileges and protections of all other citizens.

Somewhere in the statistics it was further indicated that 85% of those persons are capable of full and productive lives in the normal community of employment and activity. In other words, the rights of retarded citizens are no different than those of others. The responsibilities and protections to them should be commensurate with the full recognition of that fact.

At this point a few things should be said which are normally left unspoken on occasions like this, but one deep and abiding concern is too important to be left unsaid tonight. All of us have attended many meetings on many such subjects over the past ten or twenty years. We always leave them wondering whether the nation or the community is just creating a new profession or whether it is actually going to engender a beneficial service. I think that more than anything else we must ask our selves that question of this meeting. We have now seen, for example, what has happened to the professionalization of Civil Rights matters over just the past decade. Already the professional legalists have pushed the very meaning of the civil rights effort to a point of absurdity by posing before the Supreme Court a case which says in effect that if institutions of higher education and agencies of employment carry out the intent of the Brown decision, then they will be in violation of what the legalists now want to establish as the new meaning of the Civil Rights Act. I can well see in the near future the possibility and probability of a case which would say that any required effort or expenditure by institutions in behalf of relieving the special circumstantial problems of the mentally handicapped somehow violates the rights of the presumed mentally normal persons. How we have come to that is very simple, but nevertheless inexcusable. We have created a new profession of government related litigation.

The catalyst for that new and lucrative development was the combination of the Civil Rights movement and the address to the poor and the disadvantaged. These became too quickly dehumanized and too soon professionalized by entrusting to professionals the charge of defining for themselves the rights and needs of citizens. The result has been that the legal profession and the behavioral science research profession have come to full munificence serving each other. Researchers can produce data and interpret them so convincingly that they can serve any purpose of the litigant or the legislator.

It is a legalistic contrivance, for example, that all of the facts are not presented about the situation of the University of California at Davis or the University of Washington, or at the six universities in New York from which the DeFunis-Bakke pattern of cases emerged. Yet potentially far reaching consequences will flow from what is of record before the court, and that means that the court will respond to the limitations imposed by lawyers and litigants. One clear fact is that the range of students who were classified as special is not demonstrably different from those who were classified as regular. Another is that we have no way to assess the potential of anyone except under certain circumstances, performance and challenge, no matter what is indicated by the limited present instrumentalities of pre-test. But more important is the absurdity of invidious, special classification when the persistence to graduation and the scholarly performance of those so classified does not significantly differ from those not so classified. The crime is that legalists have been

permitted to force such classifications and then to use them to transpose the concept of enhancing opportunity into hard racially-prescribed classifications which function categorically (as at the University of California Davis) according to race rather than circumstantially according to individual need for special encouragement. Moreover, the Dean at the University of California at Davis had the special perogative of admitting sons or daughters of affluent or politically influential persons without regard to their merit and without classifying them stigmatically as special. It is of particular interest that the Bakke case was not directed at that group of five "regular" admittees instead of the group of special students. Does wealth, affluence or political influence make one automatically more academically promising and meritorius? If so, then why not force institutions to accept without question the Black and the mentally handicapped affluent and politically influential? Even the thought of this kind of gamesmanship bespeaks its own absurdity.

This pattern weighs heavily upon my mind because eighteen years ago I was privileged to become involved in the national efforts which looked so promising through the President's program called Plans for Progress involving over 300 major corporations, the legislative implementation in the U.S. Department of Health Education and Welfare, the U.S. Department of Labor and the Office of Economic Opportunity. I had a key role in developing the legislation and encouraging the formation of a major network of cooperating institutions and agencies which became the programs now known as Title III of the Higher Education Act of 1965. I have assisted the development and implementation of a comprehensive health care program for children and youth. And I have seen all of this become disturbingly over-professionalized.

We have seen the Office of Economic Opportunity and the Appalachia Commission diminished in their outreach and their effectiveness for the same reason. During that highly responsive period, all kinds of programs were established with beneficent public purpose and benefit promised from them; but as soon as appropriations of money were assigned to them, they were transformed into services of professionals and the people supposedly to be served somehow became objects rather than subjects of professional concern. More often than not, they became objects of research interest and neat rhetorical classification. Instead of being professionally served, they became objects of manipulation even for social causes in which professionals took special interest.

I risk saying these things openly and sincerely in the fond hope that we do not assemble here because we have found another population that we can manipulate to the advantage of either economic or professional interests; but rather that we will leave here in the firm commitment of ourselves and our accumulated learning and wisdom to the service of those whose lives may be enhanced by our skills and encouragement. If any of our motives are otherwise, then I submit that the behavioral scientists and the genetic engineers are already far ahead of us in capability to manipulate the disadvantaged to the benefit of themselves and their scientific interests. They already possess the capability to create life, to transform the living and to destroy all known life on this planet. Their interests do not need any further to be served.

What we should leave here thinking and pondering is that within the past fifteen years we have, through concentrating upon enlarging opportunities for the handicapped and expanding real opportunity transformed this nation into the most affluent and the most broadly educated society that civilization has yet produced. It was the Civil Rights movement which ushered this nation to the realization of the meaning of that opportunity. It was that group of small colleges and those who were educated in those colleges which ironically we only now call by the segregative term "Black" who sacrificed life and provided leadership to the nation in guiding it to that realization.

Just think, in 1960 there were only 3.6 million Americans in higher education in some 2,000 institutions. Just fifteen years later, there are 11 million Americans in over 3,000 institutions. Moreover, there are more Americans presently involved in some form of post-secondary education than there were in the total educational system in 1960. That is a remarkable achievement. In addition, the economy has expanded in ten years to a trillion dollar gross national product. In spite of inflation, poverty has been reduced and, with some obvious exceptions, the poor are better circumstanced by comparison to their status in 1960.

These results came about mainly because of presidential perception and presidential leadership when President Johnson made the nation conscious of its mutual belonging to each other, its mutual dependence upon each other, the indissoluble tie between the rights and opportunities of Black Americans and massive hidden poverty among white Americans neither of which could be resolved without address to the other. President Johnson had the Southern experience, the political acumen and the sensitive capability to make the economic case and make it convincingly. At one point he said to the corporate giants in Plans for Progress, including the Defense contractors like Norfolk Shipbuilding Corporation, that future prosperity rests upon their capability to see that the elevation of one million people from the circumstance of dependence upon public support or having no support to the level of $1,000 per capita in positive potential of tax return would yield a net gain of $14 billion to the gross national product. It only took one year for him to be able to point to that result in national net growth. Consequently, by 1965 every major sector of the society was for doing, things and programs for the disadvantaged. Only too quickly, the term itself was reduced to a hodge podge of specialties like culturally disadvantaged, ethnically disadvantaged, sexually disadvantaged, linguistically disadvantaged, economically disadvantaged and any other coinage which could produce a funded program. Subsequently, the term "minority" superceded disadvantaged because whole classes of affluent people could fit themselves under to umbrella of minority without the inconvenience or stigma of the rubric of disadvantagement. Nevertheless, all of this has somehow produced a potentially permanent positive benefit to the whole nation if we treat it that way and guard the integrity of that tremendous national achievement.

We should then spend this time examining the possibilities for opening still new vistas to the mentally retarded if we are to be impervious to the need to insure ourselves and them against the possibility of this nation relapsing either into a human relations or an economic regression. That is why in the final analysis we must give serious thought to what

Dr. Wilson addressed as being things hopefully to be accomplished before the end of this century. I would add that if we do not accomplish those things we may well not make it to the end of this century as an intact and surviving society.

Dr. Wilson spoke of those things to be accomplished in the simple but difficult to achieve qualities of compassion, of belonging and of responsiveness. He reminded us that in the past decade as our nation has become more affluent, we have become less compassionate; and we have lost our sense of belonging. It appears that the changes in our society may have divided us ever so subtlely in more ways than we were de jure divided before 1954. On the other hand, it may be that we are now more aware of the many ways in which we have been de facto divided all along. Whatever is the case, we know now that the cardinal imperative for the future is to get closer together.

If we, then, do what we should with and toward our mentally handicapped brothers and sisters across the nation and be properly sensitive to their human circumstances; and if, in consequence, we properly respond to their rights as citizens and as human peers under God and in the National family; then it would not matter much how the Supreme Court decides the particulars of the Bakke Case. We would just be reminded in the thoughts of Justice Marshall that while the Supreme Court is at any time the final arbiter of the Constitution, we, the people must know and exercise the wisdom that is appropriate to sustain this nation as a democratic society of mutually belonging human beings. James Madison, a Virginian, reminded both the Justices and the people that the Court shall be sometimes ahead and sometimes behind the general weal--that the Constitution itself shall be sometimes ahead and sometimes behind--and that therfore it requires the special will of the people themselves to govern the meaning of this nation and to translate that meaning into the appropriate human quality which will engender responsible happiness of mankind.

Those of us here assembled share a special perception, experience and, I hope, wisdom in that we realize that within our lifetime, it has been the least advantaged among the people and institutions in American who have led this nation to the most beneficent refinements of the meaning of the Constitution. We also know that it has been the most advantaged Americans who have reaped the greatest economic and social returns from those benefits. That is why it is our special responsibility and imperative to do those things which we ought to do to try to extend more of those benefits to the disadvantaged and to enlarge their share in the evolving meaning of the Constitution. That I think and hope is the real essence of the messages which came to us from Dr. Wilson and from all of our other distinguished colleagues.

HEALTH ISSUES RELEVANT TO MENTAL RETARDATION IN A MULTICULTURAL SOCIETY

by

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This country's population is comprised of people from many different ethnic and cultural backgrounds. In fact this nation was founded on principles of sensitivity to varied backgrounds, interests and pursuits. Ideally, these multicultural roots should be reflected in all of our institutions established to serve the public. Over two hundred years ago, this country's founding fathers wrote in the Preamble to the Declaration of Independence:

> "We hold these truths to be self evident, that all men are created equal, that they are endowed by their Creator with certain inalienable rights, that among these are life, liberty and the pursuit of happiness."

A real tragedy is, this is yet to be lived up to.

In terms of technology we have excelled. We can leap to the moon and Mars and back; we can move vehicles weighing thousands of pounds faster than the speed of sound; and the destructive power possessed by this nation is unsurpassed by any. Technology in science makes it possible for us to examine the inner workings of submicroscopic particles here on earth, as well as those of the macrocosm sprawled in space. Technology in medicine means X-ray vision that can see body parts on the inside almost as well as those on the outside; it means we can take out malfunctioning organs and body parts and replace them with others from other bodies or with artificial ones. Technology in education has afforded us talking typewriters, teaching machines, electronic computers and the most advanced audio-visual facilities. Our technology is together, our humanity needs help. For in view of the advances in physics, chemistry and engineering, relatively little progress has been made in sociology, psychology and psychiatry.

We have a long way to go in human relations because the relations of all humans are not yet given due respect. The principle of pluralism and multiculturalism, upon which this nation was founded, has not and does not apply to all of us. Many people and groups of people, not a part of the dominant culture, continue to be mistreated by institutions established to serve the public. All because the principle of multiculturalism is a "people" oriented principle; it's a principle of humanity rather than technology. Nowhere is this more true than in the

field of human services, where the lives, works and contributions of many cultural and ethnic groups have been looked over and over looked.

Minorities do have different and, in many cases, more life needs requiring special attention. Several of these needs are relevant to the issue of mental retardation. The needs requiring special attention begin at the inception of life, during pregnancy.

Prenatal care during the first three months of pregnancy is extremely important to the health and well-being of the mother and developing baby. While 75% of majority women seek prenatal care during the first three months, only 52% of minority women seek these services. This lack of prenatal care contributes to many medical problems. For example, toxemia of pregnancy, which jeopardizes both the mother's and the infant's life. Toxemia increases the probability of a premature delivery. Prematurity is associated with 15-20% of all cases of mental retardation. Another problem associated with lack of prenatal care is malnourishment, especially protein malnutrition. Protein malnutrition enhances the possibility of toxemia developing. Further, it retards the growth and development of the central nervous system.

Nutrition, is extremely important to the normal growth and development of the fetus. Following birth, proper nutrition plays an important role in maintaining the physical and mental health of children and adults. Our diets are related to at least six of the ten leading causes of death. The dietary habits of this country have resulted in daily per capita consumption of large amounts of sugar, salt, saturated fats, and cholesterol. The habits begin very early as adults teach poor eating practices to infants and children.

Teenage pregnancy is occuring in increasingly greater numbers. Each year, one million females between 15-19 years of age, and approximately 30,000 females under age 15 become pregnant. One fifth (over 600,000) of all annual U.S. births are to teenage mothers. Too many teenage girls and boys think you are a woman or a man because you can have or make a baby rather than because you can raise a baby. Seventy percent of teenage mothers under age 15 seek no prenatal care throughout the entire first trimester of pregnancy. This is a rate nearly triple that of 20-24 year olds. Twenty-five percent of teenage mothers under age 15 seek no prenatal care at all. Teenage pregnancies more frequently result in birth injuries, toxemia, prematurity and low birth weights.

Many medical problems can contribute to the incidence and severity of mental retardation. Socioeconomic problems also contribute to mental retardation. Socioeconomic causes result in most of the mental retardation in this society. Most mental retardation, from whatever cause, is preventable. However, the societal sensitivity necessary for its alleviation is lacking. Therefore, mental retardation continues unabated.

An interesting commentary on this society is its response to certain crises. Whenever a local community is victimized by a rash of fires or

an increase in crime, the hue and cry usually is, "let us increase the fire and police departments' allotments so we can effectively deal with the problem." When newspapers report that public school students are doing poorly on standardized exams, the hue and cry is, "let us decrease public school allotment for they are not doing what they should be doing." It is the failure of public school systems that results in much of what is called Mental Retardation.

As is usually the case, minorities and the poor suffer disproportionately from this society's failure to fully live up to its ideals. The country has had ample opportunity, both in terms of time and resources, to correct for past discrepancies and provide for present equity.

And so, there is yet work to be done for the changes that need to be made. The real arena of change is politics. Defined as the art of effecting and affecting policy, politics is significant to all group representatives seeking change. Correctable problems relevant to mental retardation, that continue to exist and disproportionately, adversely affect minorities and the poor, are a result of policies inadequate to their severe needs. The policies result from policymakers insensitive to either the severity of the problems, the minority and poor peoples, or both. Change is necessary.

Needed are policies adequate to the severity of the health and socio-economic problems of minority and poor people. Needed are policymakers sensitive to the multicultural principles upon which this nation was founded, from which this nation gets its strength and about which this nation testifies.

MENTAL RETARDATION AND

MENTAL HEALTH ISSUES

by

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Like most families with mentally retarded young adults, youth, or children, Hispanic families with such mentally retarded members are aware that (1) comprehensive services are non-existant, (2) existing services are fragmented, and (3) existing services do not generally meet the needs of Hispanics. Therefore, we propose the following goal: Prevent the debilitation and promote the habilitation of the socially and intellectually vulnerable.

The basic philosophy should be: "guide the retarded Hispano's growth toward self-actualization and social adjustment in the Hispano's home community." It should include attention to the individual's wants and interests, as well as, the professionals' assessment of her/his needs. The objective should be the normalization of the individual's life style and should include vocational competency, social responsibility, personal adequacy, education, physical needs and wants, as well as, serving her/his emotional needs; all leading toward optimal functioning in both intellectual and adaptive behavior.

RECOMMENDATIONS

1. Strict enforcement of the Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103) which states that all disabled persons have a right to appropriate treatment, services and habilitation.
2. Take certain preventive measures which will insure services needed by minorities such as:
   a) expand maternal and child health programs,
   b) provide medical care throughout pregnancy to help prevent premature births,
   c) establish health centers for preventive health care and screening for new-born infants in low income areas.
3. Sensitize guidance counselors and tests developers. They should be made aware of the fact that there are students from other cultures who speak other languages, who need special tests, not the "standardized" tests regularly administered.
4. Develop outreach programs for pregnant mothers in Hispanic communities, informing them of the causes of retardation.

5. Develop outreach programs informing parents of the sysmptoms of mental retardation and the services available for these children.
6. Most importantly, COSSMHO proposed that a comprehensive and coordinated service delivery system be developed for all mentally retarded so that assessment and delivery of services can be done through one agency and not by having to go to a dozen different agencies. This could be implemented by seeking discretionary funds from DHEW's Secretary Califano's office to fund a 2-3 year demonstration project operated by a nongovernmental, non-profit agency.

THE INTER-RELATIONSHIP BETWEEN MENTAL HEALTH AND MENTAL RETARDATION

by

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Custom dictates that an address or speech be begun with a humorous antidote; however, there is very little humor as we look at the field of mental retardation. The problems of these special people are not to give preference to wit nor does the funding commitment to them extract any banter.

There have been traditionally many controversies in the broad, complex and many faceted field of mental retardation. One of the major areas of debate was that the field belonged primarily to either education, psychiatry, pediatrics or to the social services. The valid attitude today quite properly is that those who are mentally retarded should receive the service of a team of persons with a variety of disciplines and within a variety of agencies.

Another area of controversy has involved the diagnostic and therapeutic process, the inter-relationship in working with this special group of clients. The two disabilities, mental health and mental retardation are not the same or mutually exclusive; but overlap to a great extent. The mentally retarded can and will have the same mental health problems as the general population and because of a variety of reasons there is a great tendency for the mentally retarded population to have an increased incidence of mental health problems. Their emotional problems are multiplied due to their instability and difficulty in functioning (difficulty in functioning in the home, school, work situation, and community), isolation from others in society, co-existant family problems, poor self image, family isolation, poor image by others in society, language difficulties, possible hearing difficulties, and transportation difficulties. Adding to the emotional problems is the isolation that occurs in special schools and special work programs.

If we accept the mandate of public health as being the promotion, maintenance and restoration of a state of physical, social and mental well being, then as a logical conclusion, this should likewise be the target of those working in the mental retardation field. Does not this definition of public health attain all of our goals in mental retardation? Dr. A. W. Freedman has stated that "anything intended to affect the health of populations must be within the intellectual grasp and technical competency of thousands, not hundreds of people." The attainment of public health goals should be carried out by multiple disciplines that can be performed by many persons.

There has been, in the past, and to some extent and at the present time, for providers of service to the mentally retarded to separate the problems of mental retardation from the problems relating to mental health in their retarded clients. Under this arrangement, there occured "turfism" among providers of mental health and mental retardation. The end result was that a mentally retarded consumer might often be treated and labeled at his site of entry into the therapeutic system without the collaboration of mental health and mental retardation experts. In the Commonwealth of Pennsylvania, because of the concern that the mentally retarded would possibly be "short changed" under a divided system, legislation has successfully provided that community mental health centers must have facilities for the mentally retarded--with separate funding of mental retardation services and monitoring and auditoring of service. Several community mental health agencies in that state due to concern for optimum treatment of its mental retarded clients has successfully merged their mental health and mental retardation services. This has been successfully accomplished with mental retardation union at North Central Philadelphia Community Mental Health/Mental Retardation Center with disciplines to treat both mental health and mental retardation problems. It has been our experience in the core city of Philadelphia, that 35% to 50% of our mentally retarded clients entering an out-patient facility have overt mental health problems.

Under this consolidated arrangement, we are able to give adequate therapeutic services to our mentally retarded population, using mental health disciplines as indicated as well as the other disciplines that are routinely used in mental retardation treatment facilities (speech therapy, vision testing, auditory testing, psychological testing, physical evaluation and treatment, social supports, family counseling, occupational and vocational training, and on-going total advocacy supports). Under the union of mental health and mental retardation services, the supports, counseling and therapy to the family of the mental retardation consumer is more easily effected, and more accepted by the family of the mentally retarded client. An additional advantage of this arrangement is that we have been able to add numerically to the mental retardation advocate groups. For the mental health services, advocate groups have now become automatically advocated for mental retardation services. Experience under this arrangement of some six years has proven the consolidation to be administratively and functionally effective.

There has been such emphasis placed on "rights of the retarded", "normalization processes", "dispersal from the state system" in the past years that possibly not enough attention has been placed on the mental health and total health of our mentally retarded population.

It has been well documented that the high prevalence of mental retardation among the poor and disadvantaged is unrelated to intellectual endowment of this economic class. It has likewise been documented that a disproportional number of retarded persons come from what is commonly referred to as the "culturally deprived" and that the highest proportion of this group is retarded in functions rather than endowment.

All but the most bigoted will accept the foregoing statement and if this is accepted as the prevalent and research documented view then, our battle must be against the social neglect that leads to an increased incidence of functional retardation.

We can no longer tolerate federal, state and local governments that allow the unemployment rates of Black males to be almost twice that of White males, nor can we be content with an employment rate of 25% to 40% among Black males between the ages of 18-25 years.

Our society can no longer accept poverty as it exists in our land of plenty. We can no longer accept children being isolated in segregated schools, inaccessible health facilities due to lack of transportation or cultural or language inaccessibility, sub-standard housing, polluted air, polluted streets and polluted water, inadequate schools, or racism and/or elitism in any of its forms.

The deadening influence of poverty on mental ability occurs at the moment of conception and continues throughout life.

If we briefly examine this health system and the poor, the effect of poverty becomes evident. Dr. Jack Geiger of the "Tuffs Comprehensive Community Health Action Program" stated the problem very well. He wrote, "The health of the poor in the United States and the health services available to populations in poverty--present a major on-going national disaster, a part of the special human disaster that is extreme poverty in an affluent society. We have known of the general dimensions of this disaster for a long time, just as we have known of the relationship between poverty and health, without fully facing up to either of them. The poor are likelier to be sick, the sick are likelier to be poor, without intervention the poor got sicker and the sick got poorer. And that is just what has been happening and is happening today in the central cities and the ghettoes of the urban north, the shacks of the rural south, in Appalachia and elsewhere."

If we take the Watts area of Los Angeles as an example of neglect from a health standpoint, prior to the Watts "Riots", Watts contained only 17% of the City's population, but it had almost 50% of the City's health problems. It had 48.5% of amoeba infections, 42% of food poisoning, 44.8% of epilepsy, 42% of rheumatic fever, 44.6% dysentery, 36% of meningitis and 65% of tuberculin reactors. The death rate was 22.3% higher than for the remainder of the City. It is evident that the killing had begun long before the violence of August, 1965, and it is likewise evident that the killing was due to health neglect of residents of the area. Statistics recently released by the City of New York reveal that 50% of newborns were born to unwed mothers. In Philadelphia, in 1976, 38% of newborns were delivered to unmarried mothers. The great majority of these mothers were extremely young and poor. Even in view of these facts our Congress declares that welfare funds cannot be expected for termination of pregnancy purposes.

The necessity of reporting statistics relating to the poor and health facilities and use is not necessary. You are aware that the poor utilize hospitals less than others, have less physician visits

per year, less dental visits, inadequate prenatal care, inadequate nutrition during pregnancy, less money per person is expended on their health care, the poor usually have chronic diseases, less pediatric care, greater incidence of premature births, receive less routine inoculation, and receive less routine physical examinations.

Dr. Charles Mayo has stated, "sickness makes people poor-poverty makes people sick".

You who toil in the mental retardation field and who are aware of the effect of education on functional capacity and intellectual stimulation should ask the following questions relating to our educational system: (1) do schools properly educate impoverished children? (2) should impoverished parents have some control over school policies? (3) what is the effect of segregation? (4) is textbook content orientated to poverty child orientation? (5) is teacher qualification in city core adeqate? (6) and are school facilities in core city sufficient? (7) should more money per child be expended on inner-city education?

In psychiatry and particularly in community mental health, one of the mandates is in the area of primary prevention. I submit that now is the prime time for those in the mental retardation field to become involved in primary prevention to prevent retardation by correcting the causes of retardation.

We should not diminish our battle for funding for mental retardation services; not diminish our advocacy for mentally retarded persons, continue to demand adequate schools for mentally retarded individuals, demand return to the community from state institutions, demand workshops, and all other supports for this special population.

I suggest, however, that until attention is turned to preventive services, the number of retarded persons as now classified will not decrease dramatically. Perhaps the rallying slogan should appropriately be "Prevention of Retardation", as well as "Normalization." With the present knowledge at hand on the effect of poverty and its attendant symptoms on mental retardation, there could be a great reduction in the total number--at least in the functionally retarded and with the present knowledge and the on-going research, a great impact could be made on the incidence of retardation.

I submit that you--we must fight to correct the social, economic and racial attitudes that have a documented impact on the development of retardation.

We must not be content with the present systems that are statisfied with the high rate of unemployment and underemployment among minority groups, will not be content with inferior segregated schools, will not accept sub-standard housing for the poor, must fight racism and elitism in all its forms, will not accept hunger among the poor of our affluent country.

If the battle is waged across this plain of social and economic injustices, its effect could be monumental with dramatic decrease of mentally retarded persons.

If we are then aware of the effect of poverty on the incidence of functional retardation it would seem logical that more interest, more advocacy for services to the poor would be promoted by groups both professional and interest groups involved in mental retardation.

We must become more involved in the area of primary prevention to have any impact upon the overall problem of mental retardation. If this is not done, then our only area of impact will be on tertiary prevention with minimal effect of secondary prevention. The effects on secondary prevention will be minimal as long as the retarded live in a state of poverty and are isolated from human services. There must be a broad citizen and governmental attack on the factors in our society that have such an impact on the increased incidence of retardation. These adverse factors spawn a number of other social problems.

A national commitment is not only morally indicated, but is likewise economically sound. There should be the ability of each child to be born in a healthy environment, the product of a mother with adequate prenatal care and with adequate nutritional intake, to have access to health facilities, to be able to attend a stimulating school, to live in a healthy environment with adequate food, proper clothing, and adequate housing, to grow in an environment with sufficient social service supports, to have the ability as an adult to secure a job in order to support his family and to live his geriatric years in dignity. This should be the goal of our government. This governmental position is necessary from a moral standpoint and under such a program the true greatness of this country would be realized.

Such a program does not have racial overtones for there should be concern for our total population of poor and disadvantaged. The poor and disadvantaged of our country cross all racial, ethnic, religious and geographical boundaries. Such an agenda for action is truly primary prevention in action. An agenda in which government at all levels, our religious segment, our financial leaders and all citizens should become a part.

None of us is truly advantaged as long as there are disadvantaged persons in our society, nor are any of us truly free until all members of this society have all of the advantages that our country can offer.

I suggest then, that we look at the primary prevention efforts in the field of mental retardation and to begin working to this end, and in doing so we will decrease the incidence of mental retardation as well as correct many ills in our society.

POLICY IMPLICATIONS FOR MINORITY RETARDED CITIZENS

by

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INTRODUCTION

As has been the case in the mid-seventies, the remainder of the century will witness increasing visibility of retarded citizens. The stimulus for the visibility will be all levels of government action, citizen participation and retarded citizens themselves. These activities constitute the political issues related to retarded citizens. Within this context will arise consideration of minority retarded citizens.

Throughout recorded history, persons have been described demonstrating behaviors varying from the norm. Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.[1] No single definition is comprehensive and universally acceptable. However, mental retardation is not a single disease or condition. Its causes are usually multiple and produce an impaired state in the victim. These impairments are generally recognizable through the retarded person's independent functioning, physical, communicative and social behaviors.[2]

In a multi-culture society composed of different races, the issues of mental retardation are expanded. For our discussion, minority refers to those individuals who are members of the non-dominate, identifiable subcultures. Generally, they are Black, Spanish/Mexican, Native American and Asian groups. Of course both sexes and all age levels are included. The literature best reports issues in the field regarding Black and Spanish/Mexican American groups.

As relates to the specific focus of this discussion, minority retarded citizens, the political issues are linked to both race and social class. Minority citizens, especially Blacks, experience a disproportionate share of inferior services at all levels.

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[1] Grossman, H. J. (ed.); Manual on Terminology and Classification in Mental Retardation: 1973 Revision; Baltimore, American Association of Mental Deficiency, Garamond/Pridemark Press; 1973; p. 5.

[2] Ibid.

There being fewer than 100 known Black psychiatrists in the country, Black mentally retarded citizens are frequently over diagnosed by White psychiatrists.[3] Blackwell argues such a situation makes for cultural bias against Blacks and impedes objective perceptions. A second social class linkage is that of lower class minority citizens being unable to afford the high cost of psychotherapy, psychiatric care and special education programs where not funded by public institutions. Finally, White racism is a social factor. Minorities do not receive the equivalent level of care as do Whites - both from individual and institutional levels.[4] These experiences for minority retarded citizens are mirror images of what the larger society's posture is toward the non-handicap.

Recognizing many of these problems, the late President John F. Kennedy established a select committee of scientists, educators and laypeople to propose recommendations for combating mental retardation. These recommendations formed much of the bases for governmental action in the 60's and 70's. The proposals relate to:

1. Deinstitutionalization and community services
2. Preventive health measures and research
3. Legal rights and advocacy
4. Mandatory education
5. Funding mental retardation services
6. Public awareness[5]

ROLE OF GOVERNMENT

There seems to be no legislation that has been passed with the minority citizen specifically focused. Legislation has been for handicapped persons in general with some legislation dealing directly with the mentally retarded. The generalization seems to hold true when reviewing the Congressional Quarterly Almanac from 1960-1976.

It is instructive to review the major federal legislation produced in the last decade that applies to the handicapped and mentally retarded. While state and local laws vary to a degree from federal statutes, they are complementary.

1. Aid to Education of Handicapped Act - 1975
   a. Advocated greatly expanded federal role
   b. Urged establishment of national education financial program
   c. Priority of services to most seriously handicapped between ages 3 and 21.
   d. Grievance procedures formulated
   e. Allocated $126,375,000

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[3] Blackwell, James E.; The Black Community: Diversity and Unity; New York; Dod, Mean and Company; 1975; p.265.

[4] Knowles, Louis L. and Keeneth Prewitt; Institutional Racism In America; Englewood Cliffs, NJ; Prentice-Hall; 1969; pp. 105-109.

[5] Luckey, Robert E. and Ronald S. Neman; "The President's Panel Recommendations - Today"; Mental Retardation, Volume 13, Number 4, August, 1975; p. 33.

2. Senate Bill 896 - 1974
   a. Provided for 7 million deaf, blind, retarded, speech impaired, etc.
   b. Appropriated $666,000,000
3. Rehabilitation Act of 1973
   a. Extended basic federal aid programs
   b. Authorized $1.55 billion for 1974-75
4. Civil Rights Act - 1972
   a. Extended for 5 years the Civil Rights Commission
   b. Prohibited race, religion and national origin discrimination
5. Developmental Disabilities Services and Facilities Construction Amendments - 1970
   a. Amended Mental Retardation Facilities Construction Act of 1963
   b. State formula allocation to states for construction
6. Hill-Harris Bill - 1963
   a. Funds allocated for construction and teacher training
   b. Appropriated $329 million.
7. Mills-Ribicoff Bill - 1963
   a. Prevention programs funded
   b. State aid to treatment programs

Even though the federal government has been active and motivating to induce action by state governments, the need for enhanced action at all levels is great. For example, a more intensive state and local level governmental programming for the mentally retarded, especially for the often neglected minority citizen, must be realized. Activities and programs require improved coordination for service delivery to local clients. While the Department of Health, Education and Welfare has a current budget of $144 billion, its responsibilities have a wide range of domestic service programs - and mental retardation is not a top priority.

An encouraging prospect is the newly formed Office for the Handicapped. The purpose of the agency is to coordinate development and delivery of services to handicapped Americans. To deliver this mission the Office has five functions.[6]

1. Plan long range projection for the provision of comprehensive services
2. Continually analyze the operation of HEW programs, and evaluate their effectiveness
3. Encourage coordination and cooperative planning among HEW programs
4. Develop ways to promote the utilization of research findings and the adoption of exemplary practices
5. Serve as a central clearing house for information and resources available to handicapped persons

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[6]Thomas, Stanley B.; "Citizens and Handicap"; A Keynote address delivered by the Honorable Stanley B. Thomas, Jr. at the National Eastern Seal Society's Annual Convention; November 13, 1974; San Antonia, Texas.

ROLE OF CITIZENS

Indeed the community has an obligation to the mentally retarded aside that of responsible government. Here the notion does not separate the mentally retarded from other members of the community. All are part. However, due to the already established differences experienced by Black and other minority retarded, special consideration needs to be made.

A primary role of the community is to act in advocacy for the minority retarded citizen. This role requires an enlightenment on the part of many citizens to better understand the facts of mental illness. Persistence of beliefs in the traditional myths serves to hinder effective advocacy for minority retarded people. Secondly, advocacy requires the community to participate in national and local planning activities that will affect the minority retarded. Thorough planning presents an excellent means of preventing many of the injustices currently experienced by the oppressed minority handicapped citizen. Finally, the community can involve itself through participation in programs geared for the mentally retarded. Such involvement might be realized through the planned Virginia Minority (Retarded) Affairs Coalition. Especially would such an organization prove beneficially to the minority individual as a special interest group.

Professional elements of the community include researchers and social service delivery personnel. Scholars and researchers have the responsibility to make more objective, fact-based evaluations of minority retarded people. Cultural and social prejudices must give way to thorough diagnosis. Simply, culturally biased tests ought not be sufficient to warrant mental retardation labelling.[7]

Social service agents must generate more effective and efficient means of serving the minority retarded citizens. For example, the over-representation of minority retarded citizens in special education programs suggests low socio-economic status may be more critical a criteria for placement than mental condition.[8] Thus, service personnel need to assume less of a patronizing posture for a competence-based position in working with minority retarded citizens. Clearly, this is a reasonable suggestion to eliminate program discrimination against minority retarded citizens.[9]

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[7]Steinback, E.A.; Beerman, L. L.; Belhamy, G. T.; DiRocco, P.; Foss, G.; Friedland, M.; "Civil Rights of the Mentally Retarded"; Law and Psychology Review; Spring, 1975; pp. 151-178.

[8]Warren, Sue Allen and David C. Gardner; "Teacher Nomination of Minority and Low Socio-Economic Status Students for Special Education"; Education, Volume 96, Number 1, Fall, 1975; pp. 57-62.

[9]Conley, Robert W.; The Economics of Mental Retardation; Baltimore, John Hopkins University Press; 1973; p. 21.

Though to be different in tactics, the mentally retarded community may well consider a new militancy fashioned in the spirit of the Civil Rights Movement. No matter one's condition, in a pluralistic society, it is necessary to articulate demands in a convincing manner. This clearly means that self-expression is necessary because other-group advocacy is nearly always constrained by competing special or self interests.

Needed are mentally retarded people who have been educated and trained in the art of self-articulation on issues of self-determinism. Such a proposal demands retraining of teachers of the mentally retarded.[10] This suggestion is not bold when considered in light of the fact that many mentally retarded people could be on their own.[11]

SUMMARY

This presentation has posited that issues relating to mental retardation will be a political force for the remainder of this century. In reviewing policy implications for minority retarded individuals, three activities were focused upon. Three policy statements appear germane to the issues presented.[12] They include:

1. All levels of government must commit to greater intensity of policy and programs specifically aimed toward the unique problems associated with minority mentally retarded citizens.
2. Community individuals need to serve in advocacy as educators, planners and program participants on the behalf of minority retarded citizens.
3. Minority retarded individuals must formulate self-determining, special interest groups to demand redress to relevent problems.

Indeed these are minimum social change proposals.

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[10]Jordan, June B.; "Striving for Excellence in Educational Progress and services for the Mentally Retarded", Education and Training of the Mentally Retarded, Volume 9, Number 3; October, 1974, p. 163.

[11]"From Institution to Community Living"; in Research and Demonstrations Brief; published by Office of Research and Demonstrations; Social and Rehabilitation Service; Department of HEW; 1972.

[12]See a well documented case for a non-Western Community in Community Resources for the Mentally Retarded: New Delhi; Central Institute of Research and Training in Public Cooperation, 1972; pp. 137-150.

POSSIBLE CAUSES OF MENTAL RETARDATION

IN PUERTO RICO AN ISLAND'S CHALLENGE

by

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INTRODUCTION

To present a paper on the possible causes of mental retardation in Puerto Rico may seem redundant since mental retardation is, in the last analysis, the overt manifestation of subaverage general intellectual functioning. And, although very little is known about the true nature of intelligence, there seems to be agreement that it transcends nationality, race and ethnicity. Therefore, logically, the causes of mental retardation should be universal, not national ones. However, a person's intelligence, whether subaverage, average or above-average, is deduced from his visible behavior. This behavior is always the product of environmental and hereditary factors. The environmental components of intelligence and any related subaverage intellectual functioning reflect the culture--customs, values, folklore--of a given country. These cultural elements are unique and specific.

In this paper I shall attempt to analyze those aspects of the Puerto Rican environment and culture which may influence the intellectual development of its people. I shall also discuss briefly a proposal designed to enhance the intellectual development of a segment of this population: the rural disadvantaged. In order to better appreciate this paper I shall examine the historical background of Puerto Rico.

Brief Historical Background: Puerto Rico is a Spanish-speaking, rapidly developing island; politically and economically tied to the U.S.A. Like many rapidly developing countries, Puerto Rico is characterized by overpopulation (763.4 inhabitants per square mile), high unemployment (12%-30%), a high cost of living with a low salary scale and high index of poverty. The average per capita income is $1,842 (1977). Puerto Ricans are the products of the mixture of three major races, (Caucasoids-Spanish, Negroid-African and Mongoloid-Indians). They may seek their roots in continental Europe or Africa. But their main root is indigeneous, and springs from the Indian culture, the Taino, or Borinquen. At this juncture, I must point out that neither racial prejudice nor bilingualism emerge as causative factors of reduced intellectual performance of children in Puerto Rico.

This paper is based on data obtained from reports on those diseases--physical and social--which seem to be closely associated with adverse socio-economic conditions and therefore, as regards their possible relation to mental retardation, may be peculiar to the Puerto

Rican setting. These physical diseases are gastroenteritis, tuberculosis, syphilis; and the social disease, drug addiction.

PHYSICAL DISEASES

Gastroenteritis: Although during the last ten years the overall average rate of infantile mortality due to gastroenteritis has dropped from 60.1 to 38.2 per 100,000, within this time there have been periods in which the total infant death rate under one year of age due to this disease has been alarming.

Tuberculosis: Tuberculosis is no longer a major cause of death in Puerto Rico (it ranks about eighth); nevertheless, its prevalence in the Puerto Rican population justifies its inclusion in this paper.

Syphilis: The incidence of syphilis in Puerto Rico is a cause for great concern. According to the Puerto Rican Department of Health, each year there is an incidence of 2,5000 cases of primary syphilis. These figures do not include cases with other venereal diseases.

SOCIAL DISEASES

Drug Addiction and Alcoholism: In Puerto Rico, drug addiction and alcoholism have been described as an epidemic disease. The number of known heroin addicts has increased from 1,600 cases in 1961 to over 13,000 or more cases in 1974. There are an estimated 50,000 alcoholics in the Island.

Although drug addicts and alcoholics are found in every strata of Puerto Rican society, the highest prevalence of reported cases reside in the lower social and economic levels of Puerto Rico. As to a direct causal relationship between these social diseases and subaverage intellectual functioning, we can only make conjecture.

Children reared in a drug addict subculture would be victims of the nocious effects of that environment which could cripple their physical, emotional and mental growth and reduce subsequent intellectual functioning.

Let us now look briefly at the results of studies carried out on pre-school, school and post-school populations.

This portion of the paper is largely based on referrals to the Puerto Rican Diagnostic and Orientation Center for Retarded Children. All initial diagnoses were made by one of the two pediatricians who work on the team, which is composed of a psychologist, a social worker and a registered nurse.

Practically every type of mental retardation was found among the children attended at this center including those rare clinical cases attributed to chromosomal and metabolic anomalies. At least four interesting points emerged from this study: (1) that 21% of the cases were diagnosed as having Down's syndrome (mongoloids); (2) that approximately 4-5% of surviving cases of gastroenteritis were diagnosed as mentally retarded; (3) that according to the Director, at least 15-17%

of these cases were preventable; and (4) that although this center's services are open to the general public and it receives referrals from private practitioners, at least 80% of all cases diagnosed as mentally retarded (mostly clinical and severe types) proceeded from low income families.

I shall now present the findings of a study based on a school-age population.

Study of School Population: The possible causes of mental retardation of the school-age population (6-18 years) were obtained from a study of 599 school children (57% males, 43% females) suspected of being mentally retarded. Each child was examined by a pediatrician and a psychologist and his parents were interviewed by a trained social worker. These children were chosen from an area sampling of the island. The most salient points gleaned from this study are: (1) that approximately 90% of the confirmed cases of retardation were from culturally deprived areas; (2) that 47% of the children were diagnosed as being undernourished; (3) that 75% of the children were born at home (11% of the mothers were attended by a doctor or a nurse, the others by midwives); and (4) in approximately 53% of the cases, neither the medical examination nor the social workers' reports could provide any possible explanation for the children's low intelligence. The result of this study motivated a more-in-depth study of a post-school population.

Post-school Population: The data from a post-school population were obtained from a recent study of 4,771 adults, ages 23-49, who were selected from a random sample of the Island. The sample was divided into community types: Peasant, plantation, urban slum, lower middle, middle and upper middle classes. Each person was given, in Spanish, an individual intelligence test (Stanford-Binet, Puerto Rican version). From this study we obtained the following picture: (1) that 2,800 were classified as probably retarded; (2) that in every community there was a higher prevalence of retarded women than men; (3) that approximately 51% of the peasant community, 61% of the plantation and 30% of the urban slum areas were classified as retarded--only 1.9% of retarded adults were found in the urban middle and upper classes; (4) that the average annual family income of the retarded group was approximately $1,400 (range $1,100-$2,420).

A cursory analysis of the reports and studies presented show that in Puerto Rico, the same causative factors of mental retardation are operating as in the U.S.A. but, in all probability, in different dimensions. Poverty and its major concomitants--substandard housing, inadequate diet, inferior prenatal, perinatal and postnatal care, high index of communicative infectious diseases, poor sanitation and others--is the one factor which stands out as the major difference between the Puerto Rican and U.S.A. populations.

The noxious elements of poverty may reveal themselves as retardants and suppressors of intellectual development and repressors of positive motivational attitudes towards academic achievement and learning, especially those things which a child feels are irrelevant to his modus vivendi. If this is true, we should find some evidence of substantial

differences in the overall intellectual functioning of members of economically advantaged societies and those of economically depressed one (rich vs. poor).

Comparative studies between culturally different countries are fraught with a host of unmeasurable variables and evidence based on the results of such studies is rarely conclusive. Despite their obvious limitations, comparative studies provide basis for formulating hypotheses and for stimulating a program of action.

Cross-cultural Studies: In a cross-cultural study of 10,000 American and 20,000 Puerto Rican school children tested with parallel versions of a general ability group test (Inter-American Test of General Ability), a significant difference between the median scores in favor of the American children was found at all age levels. For example, the median American score at six years was 81, as compared with 55 for the Puerto Rican. Every attempt was made to minimize cultural influences on test results, and each child was tested in his vernacular.

On the Puerto Rican version of the individual test, Wechsler (WISC), the average I.Q. is 88, SD 21.6, as compared to the average I.Q. of 100, SD 15, on the American version. The distribution curve, however, is similar for both populations. A comparison of American and Puerto Rican Wechsler (WSIC) I.Q.'s is seen in Table II.

Significant differences were also found on using the Puerto Rican version of the Stanford-Binet, the WAIS and the non-verbal test, Raven's Progressive Matrices. It should be pointed out that according to the statistical data for the Puerto Rican version in Spanish of the Stanford-Binet, 25% of Puerto Rican children have I.Q.'s below 83, as compared with 9% of American children.

Some of the differences in the performance of Puerto Rican and U.S. children in similar intelligence tests may be spurious since errors inherent in test adaptation and translation from the one culture to another may have influenced Puerto Rican children's scores. Nevertheless, we cannot exclude the possibility that these differences are a reflection of the prevailing socio-economic conditions in each country. And, since these above-mentioned tests are being used in Puerto Rico to identify, diagnose and classify children as mentally retarded, we cannot minimize the importance of the discrepancies between the scores of American and Puerto Rican versions of the same intelligence tests, especially those on the Binet and WISC. According to results in these latter tests, approximately eight percent of Puerto Rican children could be classified psychometrically as mentally retarded as compared with approximately three percent of American ones; that is, those having an I.Q. of 70 or below. More in-depth causes of the difference in average I.Q. scores on these tests, and the advantages and disadvantages of using their results as criteria for diagnosing retardation in Puerto Rico.

Let us summarize our data.

SUMMARY

The principal objective of this paper was to identify possible causative factors directly or indirectly related to mental retardation, especially those which might be peculiar to Puerto Rico. Various physical and social diseases were singled out as possible contributory factors to mental retardation; and results of studies carried out in Puerto Rico at the various age-levels, and those from comparative studies of the performance of Puerto Rican and North American children on similar tests of intelligence were presented and discussed. It was suggested that poverty with its concomitants, malnutrition, poor housing, inadequate health facilities and others, stands out as the one factor which may be related to intellectual development and subsequent mental retardation in Puerto Rico. It is not suggested, however, that poverty is unique to Puerto Rico and non-existent in the U.S.A.; rather, it is the degree and extent of poverty in the island which may have left an indelible and pernicious effect on a given segment of the Puerto Rican population--the disadvantaged retardate.

MEETING THE CHALLENGE

The Puerto Rican Governement is conscious of the socio-economic problems that impede the full intellectual growth of its young citizens. May I intercalate a positive note in our discussion: That Puerto Rico has one of the highest standards of living in all of Latin American; that despite prevailing adverse socio-economic conditions in an Island of 2,900,000 inhabitants, approximately 1,000,000 students are enrolled in schools and universities; and that there are 3 major universities with a combined enrollment of over 100,000 (105,426) students. Yet these encouraging figures should not be used to mask the problem of the prevalence of subnormal children in the disadvantaged areas of Puerto Rico.

Three government agencies are directly dedicated to eradicating or at least mitigating the effects of poverty. These are the Departments of Health, Social Services and Education. I shall limit my paper to only one agency: Department of Education, although, this is not meant to minimize the efforts being made by the others.

More specifically, I shall present a resume of a project entitled A Proposed Plan to Raise the Achievement Level of A Selected Group of Disadvantaged Elementary Public Students in Puerto Rico. This project has just been initiated (this semester, 1977), at the College of Education, University of Puerto Rico, Rio Piedras. I must point out that the Proposal is not designed to eradicate mental retardation in Puerto Rico. Indeed, the terms "mental retardation" or "mentally retarded" do not appear in this Proposal! However, on discussing this plan with the project consultant, he observed that the vast majority of the target population of this Proposal is functional mental retardates and that without special education assistance they would seem to be potentially permanently mentally retarded.

I frankly feel that, at present, in Puerto Rico we do not possess sufficient evidence, refined instruments or specialists to make a differential and conclusive diagnosis or prognosis between children in disadvantaged area who are underachievers or backwards and who may be

"temporarily retarded", and those who are proven to be permanently retarded. We are not convinced that mental subnormals can be divided into: the mentally retarded or the mentally defected on the basis of the presence or absence of detectable CNS pathology. Although we have no research data, we cannot accept the theorem of fixed heritable I.Q.'s. We conceive mental retardation as a pattern of human behavior, and therefore, it is dynamic. We are impressed and stimulated by studies which suggest that this behavior can be improved especially when treatments are begun early in childhood. Thus, the general and primary objective of this proposal is to raise the achievement level in a selected group of 8,931 disadvantaged elementary school students of grades 1-3 who live in rural and largely isolated areas of the Island. As I aforementioned, previously, studies have indicated that it is in these areas where the incidence and prevalance of mental retardation are the highest. The vast majority of these children's school achievement is significantly lower than the Island norms for their grade level. It is hoped that the raising of the achievement level of these disadvantaged children will stimulate intellectual performance which over a period will result in the reduction of the incidence of mental retardation in the adult population.

How is this to be achieved?: Briefly:

1. The College will go to the people! This is a possible innovative feature of the project as all activities will be carried out in the actual schools.
2. There will be an increase in school instruction in these schools from three hours a day to six hours daily.
3. Teachers will be trained in the theory and application of individualized instruction. This will be done in many cases by Special Education Staff.
4. Teacher Aides will be trained and provided, one to each classroom teacher.
5. Parents will be orientated as to the aims and activities of the proposal.
6. Research and Evaluation.

RATIONALE

Increased school instruction should expose the disadvantaged child to an increased, stimulating educational environment and to a decreased time exposure to the noxious effects of poverty.

--The judicious implementation of individualized instruction will reduce the effects of heterogeneity and lead the teacher to treat the individual student, stimulate personal effort and capitalize on increasing mental growth resulting from increasing chronological age.

--The orientation of parents and the community is a vital component of the proposal. This will largely involve assisting parents in realizing their role in their children's mental development, the activities which can enhance this development and those which can arrest it; it will also mean the planning of enriched community activities; both recreational, cultural and intellectual.

As regards research, concurrently with this proposal, a team of researchers will conduct a study of the "State of Child in Rural Puerto Rico". The information gathered from this proposal can be incorporated into a general study aimed at a broader assessment of the influence of environmental factors in the total Puerto Rican population.

--Finally, evaluation should provide at least part answers to the question "Will the enrichment in the early school child's educational life result in a significant raise in his academic achievement? Will this raise be continuous and lead to increase intellectual performance? Finally, will this increased intellectual performance be revealed in a decrease in the incidence and prevalence of functional retardates in the adolescent and adult Puerto Rican populations?"

We at the Puerto Rican College of Education are enthusiastic, but realistic! We will need your support. Indeed, we welcome it. And, we sincerely hope that if and when we convene again we shall be able to make a more substantial contribution to the prevention of mental retardation in disadvantaged societies.

SUMMARY REPORTS

GROUP 1A

PREVENTION OF ENVIRONMENTAL CAUSES:

BIOMEDICAL AND HEALTH RELATED ISSUES

The overall stance of Group 1A on prevention of MR among minority populations is based upon the belief that historically, inequity has existed in service efforts available to the majority and minority populations.

The overall intent of the specific recommendations is to reflect the group's belief that minority MR needs can be met by an effort which integrates a greater responsiveness of existing service and support structures to the MR needs of minorities and the initiation of specific service efforts trageted at the production of programs, service development strategies and manpower development responsive to articulated needs of minority populations.

In this context services must respect the human dignity of the minority individual; and health care services must be both available and accessible to all minority persons regardless of place of residence.

General Recommendations

1. Increase funding to assist existing programs and foster new programs for delivery of health care to improve the quality of life of minority group populations.
2. Insure significantly increased minority representation and participation in the planning and delivery of health care service efforts at federal, state and local levels; that is manpower development through educational opportunities and effective use of skills of minorities on advisory committees (e.g. PCMR), in helping professionals, etc.; and that there be no intraminority group discrimination based on sex (presently Black males are often overlooked), or based on cultural group. The group reports additional recommendations in two broad areas:

1. Extension of existing services to reach minority populations:
   a. Instill respect for human dignity which is based on a sound knowledge of cultural and ethnic groups and on understanding of each other.
   b. Effect greater utilization of the existing human services systems to render services to minority populations. One means by which this can be accomplished is through the promotion of cooperation between separate entities within the health care system including the use of the clearinghouse concept and giving special attention to the establishment of cooperation between public and private agencies. Another means of cooperation is through broker advocacy--assuming responsibility for getting the client to the needed service, no matter the level at which he enters the system.

c. Provide information and education. Implement public awareness programs relative to existing services through media and language responsive to differences among populations, (e.g. Spanish for a Puerto Rican, TV for a poor reader). It is also necessary to educate the professionals relative to the nature of and services for mentally retarded persons, especially those among minority populations. Develop new and innovative methods of effective delivery of public awareness programs for minority populations.

2. Establishment of new services specific to needs of minority group populations:
   a. Develop comprehensive preventive health care systems which are responsive to the special needs of minority group populations (e.g. recognize sensitivity of some groups to genetic counseling).
   b. Develop and emphasize instruction on procreation and family life to promote understanding of consequences of behavior and concomitant responsibilities.
   c. Develop systems for early identification of mentally retarded among minority populations and differentiation of mental retardation from some of its correlates evident in these populations.
   d. Make new uses of existing human resources. This includes available persons with skills to offer, such as, retired persons and minority youth. It also includes involvement of groups such as civic and educational organizations, as well as labor unions in the prevention of mental retardation.
   e. Establish research programs. Engage in basic research relative to the prevention and treatment of mental retardation among minority populations and also research programs to improve recognition and articulation of services needed by minority populations.
   f. Implement and enforce systems of accountability of the delivery of health care to minority populations and evaluate efforts to ensure that there is improvement in the target groups.

GROUP 1B

PREVENTION OF ENVIRONMENTAL CAUSES:

SOCIOCULTURAL ENVIRONMENTAL ISSUES

Recommendations

Representation. That minority individuals from low socioeconomic levels represented by parents of persons with mental retardation, persons with mental retardation, as well as advocates for persons with mental retardation be included in decision-making processes on local, state and federal levels; on groups, and committees including the President's Committee on Mental Retardation which have concerns with programs dealing with their total welfare.

Legal Services; Supportive Services. Proper legal assistance and supportive services, specifically legal advocacy within the community related to contractual agreements, consumer information and usage, and all business transactions should be provided.

Local Minority Community Organizations for Aid to the Disadvantaged. Groups emphasizing parent training, local needs for the developmentally handicapped, and "How to" package regarding consumer information should be expanded locally or implemented where there are no services, and should be comprised of residents and parents at the neighborhood level. These would purposefully involve social, political-pressure and clergy groups. This would aim at greater facilitation of communication at the local level.

Funding should be available for consumer advice and counseling with special emphasis on nutritional information with out-reach to minority disadvantaged pregnant mothers.

Education. Emphasis and diagnosis of disabling conditions, specifically, mental retardation should be on particular needs and characteristics of the individual. Diagnostic labels should not be used in a discriminating manner, but only as an aid to providing needed understanding or utilization of services.

Greater emphasis should be placed on appropriate and adequate training of professionals and para-professionals in health care fields, including welfare, medicine, mental health, nursing, etc. There should be special emphasis on prevention, diagnosis and treatment of the mentally retarded, especially in the minority disadvantaged areas. This should include seminars and courses related to value systems affecting the professional and para-professional's treatment in dealing with the mentally retarded with special consideration on minority disadvantaged groups with cultural diversity. Certification and licensing requirements at national, state and local levels should reflect this training and awareness.

Greater incorporation into governmentally-sponsored informational media such as books, papers, movies, textbooks, encyclopedias and

reference books of a more relative and positive attitude toward the mentally retarded and developmentally disabled person, with emphasis on the positive contributions of these groups to the overall society.

Nutrition. Because of the known and suspected effects of inadequate or harmful nutritional practices on the new-born and unborn child, nutritional training and emphasis should be expanded and/or implemented at various levels of the educational system, for both laymen and professionals.

Needed nutritional consultation and expertise should be appointed to governmental agencies that deal with the developmentally disabled from minority disadvantaged populations, specifically the President's Committee on Mental Retardation.

Medical - Health. Implementation and/or expansion of family planning information, proper parenting courses, sex education, at appropriate levels of public education, specifically, beginning at the grade school continuing through the high school level.

Implementation and/or expansion of programs for family planning, genetic counseling and prenatal diagnostic clinics with out-reach programs to enable reaching minority disadvantaged populations.

Implementation and/or expansion of maternal - child care facilities with special emphasis on early diagnosis and preventive measures to combat and recognize the causes of mental retardation. Whenever possible, the developmentally disabled child should be integrated into these facilities.

Environment. In view of the environmental agents, such as lead, which is known or suspected to be a causative factor of mental retardation, structured inforcement of needed legislation to protect individuals from environmental pollutants is needed. Those who refuse to correct these deficiencies (slum housing with peeling lead containing paint chips) should be required, by law, to take effective measures to alleviate the situation or face appropriate legal penalties and be liable for the subsequent health care of the guilty parties.

Employment. Implementation of pre-career activities at the high school level for students from low-socioeconomic levels in programs aimed at creating prevocational training attitudinal awareness, and awareness of causative environmental factors of mental retardation by the use of already subsidized monies from agencies such as the Concentrated Employment Training Act (CETA), On Job Training (OJT) and Manpower Programs. The opportunity for employment would be at centers for the developmentally disabled with emphasis on high school credit for the services rendered.

G R O U P 2 A

ECONOMIC AND POLITICAL CORRELATES - ECONOMIC ISSUES

Recommendations

1. Increase and intensify methods of fostering community acceptance of mentally retarded persons.
2. Engage in cost-benefit analysis in order to determine which modes of delivery of service are most effective.
3. Increase research monies for projects which investigate methods of reversing mental retardation which occurs as a result of economic disadvantage, and, the identification of factors which lend themselves to primary prevention of retardation.
4. Increase self-help capabilities and job readiness skills for the older retarded citizens as a method for promoting normalization.
5. Increase the advocacy role of minority groups on behalf of the mentally handicapped.
6. Involve the mentally handicapped, who are capable of becoming their own advocates for increasing self determination.
7. Encourage on local, state and federal levels, additional resources for research, programming and implementing by minorities, for the mentally handicapped minorities.
8. Encourage sponsored research at the historically Black colleges, with resource technical assistance from such organizations as Moton Memorial Institute.
9. Encourage the federal government to provide funds for needed technical assistance in writing proposals, proposal monitoring through the funding systems, maintaining the funded project and disseminating research results, position papers, books, and teaching materials.
10. Encourage the federal government to provide funds for increasing the quantity and quality of Black teachers in special education at predominately Black collleges and for providing release time for conducting quality research.
11. Provide a linkage system between the faculties of the predominately Black colleges and Black faculty members of predominately White colleges for the purpose of better communication, research and dissemination of research information.
12. Encourage majority groups involved in pre-service and in-service training programs to utilize Black colleges for retooling personnel and faculty to effectively meet the needs of disadvantaged and mentally handicapped minorities.
13. Provide supplementary funds for practicum sites for those who are in training in special education and other related fields.
14. Provide funds for reducing the current pupil/teacher ratio of regular classes, subsequently providing for individualized instruction for <u>all</u> children, which most likely will reduce the chances of many minority group children being identified as mentally handicapped.
15. Make provisions for involving Blacks and other minorities in deciding priorities of research focus and funding patterns.

16. Give higher priority to the focus and funding of delivery systems that provide adequate nutritional education and practices, with emphasis on pre and post-natal care among minority groups.
17. Coordinate existing and future programs/projects which serve to improve the quality of life of mentally handicapped minority groups.

M I N U T E S

W O R K S H O P 2 B

POLITICAL AND ECONOMIC CORRELATES-POLITICAL ISSUES

The participants in this workshop spent much time attempting to define what issues are political and/or economic in nature. Most felt that any problem in the service delivery system had its roots in the political or economic systems.

After much discussion, it was ascertained that most of our concerns were reflected in Chapter 5, "Prevention: The Right to a Good Start in Life" of the March, 1976 Report to the President from the President's Committee on Mental Retardation. Thus, a new concern evolved in that if the President's Committee on Mental Retardation has reported our concern, why do these concerns still exist? Our discussions led to conclusions reflected in the following general recommendations.

1. The general public, specifically the proposed recipients of available services need to be made aware by national, state and local agencies and organizations of what is available by more direct means than those currently utilized. Therefore, we recommend that these agencies, including the PCMR, be required to submit relevent information to prospective recipients through responsible agents in such a way that prospective recipients will be cognizant of what is available.

2. Objective #IV -- It is recognized that funds are available for implementing programs to alleviate cultural conditions contributing to retarded development. However, the funds have been managed in such a way as to reduce maximum benefits to the proposed recipients. Therefore, we recommend that individuals who have established their interest and concern for the recipients of funded projects be assigned to the task of controlling the allocation of funds to assure maximum benefits to the recipients.

3. Objective #I -- In view of the fact that efforts to promote normalization among the mentally retarded have not materialized due to members of society erecting barriers to prevent those categorized as mentally retarded from actively functioning in their communities, we recommend that concerned individuals function as committee of one, and also as organizations to develop attitudes at local, state and national levels that will accept deviance as a normal aspect of life as projected by behaviors allowing and encouraging maximum functioning of retarded individuals in their communities.

4. We recommend that community and local advisory boards represented by those in need of services be established to disseminate information, develop plans for acquiring services, and supervise the implementation of the services.

5. In view of the general trend to relegate those of Hispanic origins to the category of "and others" in statistical reports, it is recommended that a seminar or a similar operation be established so that specific needs of the Hispanics may be identified, and appropriate services rendered.

The resource/consultant identified four areas or issues which would be considered political or economic. They were:

1. Unemployment and training for the handicapped
2. Viable strategies for involving the mentally retarded or of getting representation for the mentally retarded in all levels of the political system
3. Educational opportunities for the handicapped
4. Identification of the political benefits for supporting the mentally retarded

Other Recommendations

1. Unemployment and training for the minority handicapped. Workshop 2-B recommends that PCMR go on record in support of full employment for all persons. Additionally, the workshop recommends that under the full employment program, the following components exist for the handicapped:
   a. A job bank
   b. Supportive work programs
   c. Education and training for the community to accept the rights and abilities of the mentally retarded

2. Representation for the mentally retarded. Workshop 2-B recommends that the PCMR encourage the use of all kinds of volunteer organizations in the mentally retarded movement. This will increase their awareness of mentally retarded and problems in service delivery and, thus, increase the number of persons who vote and who are sensitive to the mentally retarded. These groups can then help in putting pressures on all levels of government.

3. Educational opportunities for the handicapped. Workshop 2-B recommends that PCMR support full funding for P.L. 94-142, thus, insuring the rights of the handicapped, including the MR to education which will develop all of their potentials.

4. That PCMR support the continuation of developmental disabilities projects under P.L. 94-103, however, it should monitor the developmental disabilities office to insure minority representation in groups getting funds. Other issues discussed in the workshop which did not resolve themselves into recommendations were:
   a. Labelling and mislabelling of the mentally retarded
   b. Research on the feasibility of establishing a department on mental retardation
   c. The need for communities to organize and deal with local issues related to the mentally retarded
   d. The strong role advocacy must play on both the state and federal levels

e. The necessity of preparing classroom teachers for the eventual mainstreaming of the minority handicapped child
f. Public attitude and its effect on the mentally disabled

5. Be it recorded that the participants of this seminar strongly recommend the continuance and/or development of effective action programs in all segments of this society, particularly in the areas of employment, post-secondary education, and professional schools. Given the strong correlation that exists between economic conditions and the incidence of mental retardation, particularly the milder forms, the federal government must adopt and implement a full employment program in which cultural and ethnic minorities achieve the same unemployment rate as the White majority.

SPECIAL RECOMMENDATION ON ETHNIC MINORITY REPRESENTATION TO THE PRESIDENT OF THE UNITED STATES

by

Economic and Political Issues Workshop Group

At the Multicultural Seminar on Mental Retardation among minority disadvantaged populations on October 11, 1977, a recommendation is presented by the Economic and Political Issues Workshop Group to the General Assembly; the body of the recommendation is as follows:

This conference recognizes that racial and ethnic minority groups have been consistently excluded from meaningful participation in decision-making policies at all levels of government activity.

Furthermore, there exists an urgent need to include full representation from all of the groups affected by these policies with respect to decision-making or advisory groups that affect services.

Therefore, it is recommended to the President of the United States that it is imperative that the following action be taken:

1. That racial and ethnic minority groups be represented on the President's Committee on Mental Retardation, National Advisory Council on the Developmentally Disabled, President's Committee on Mental Health and other Presidential and Federal level councils, commissions or committees related to mental retardation and that these groups be represented by minority members in a proportionate amount equal to the demographic area.
2. Be it further resolved that this level of representation of racial and ethnic minority groups on decision-making, policy making bodies must be extended to councils, commissions, and committees and agencies at the state and local levels who relate to mental retardation or developmental disabilities services.

3. To guarantee a standard of equity and justice for all poverty ethnic minorities who suffer impaired mental development and other disabilities. It is therefore, recommended that the PCMR initiate actions to plan and sponsor specific seminars for the Hispanic(s) population as it has been done for other ethnic minorities. Special socio-cultural and linguistic barriers exist within this population group in addition to environmental, poverty, and ethnic discrimination. Therefore, be it resolved that the PCMR respond to this request and recommendation and that all known Hispanic groups be notified and invited to participate at this seminar.

It is expected that all of the recommendations presented at this conference be also given to your U.S. Senator and Congress persons so that he/she will know that their local constituencies are in support of these matters of concern that affect racial and ethnic minorities representation on these high level councils.

G R O U P 3 A

PHILOSOPHY OF AN IDEAL SERVICE DELIVERY SYSTEM

The ideal service delivery system embodies a humanistic approach. This approach is manifested through responsiveness and a level of sensitivity which recognizes and accepts cultural pluralism as a major factor in providing services. The system mandates a basic respect for individual and family worth, rights and dignity, recognizes and supports individual differences, and is flexible enough to respond effectively to the full spectrum of human behavior without making value judgements. Quality is a paramount concern with services provided in a manner to fully encourage the attainment of maximum potential. The system further consists of a specific set of characteristics, service components and outcome expectations.

CHARACTERISTICS OF THE IDEAL SERVICE DELIVERY SYSTEM

--Displays a knowledge of and a sensitivity to the diverse cultures it serves.
--Attracts and retains highly skilled and motivated staff.
--Effectively involves the total family in the service process.
--Encourages a self-help/self-determination focus among its clients.
--Provides a comprehensive and coordinated set of services.
--Established and maintains a two-way flow of information between its community and staff. Establishes a multicultural information network and communication channel, with east and west clearing houses, which would collect and share information and materials, as well as serve as resource banks for minority manpower relating to developmental disabilities.
--Acts as an advocate for the identification and resolution of consumer concerns.
--Dynamically utilizes monitoring, evaluation and research as tools for self examination and improvement.

PRODUCTS OF THE IDEAL SERVICE DELIVERY SYSTEM

--Develops and maintains highly trained, skilled and motivated staff. Trains professionals, para-professionals from minority groups specifically to work with mentally retarded persons.
--Fosters close family involvement in the service program--utilizing them in advisory, decision-making and provider roles. Trains parents from the minority groups to work specifically with mentally retarded persons. Makes a special effort to include parent involvement and participation.
--Creates an environment in which the dynamics of self-worth, self-determination and self-help are motivated.
--Enjoys the community's confidence as its advocate.

--Provides consumers with the necessary tools for successfully coping with their environment.
--Achieves coordinated and comprehensive set of services including programs of early intervention in the low income minority groups and comprehensive information on prevention in the media, especially radio and television.

G R O U P 3 B

ISSUES RELATED TO MANPOWER TRAINING AND TECHNICAL ASSISTANCE

General Affirmations

Group 3-B participants wish to affirm without repeating a total agreement with the global objectives as set forth by the special task force on Environmental Prevention as stated in Chapter 5 of the report, MR: 76, Century of Decision.

Secondly, these participants feel that the objectives for this conference were viable and comprehensive. Information presented through general sessions made it possible to understand the complex nature of the area of cultural diversity as a determinant in planning and providing programs for MR persons and their families. Group 3-B was fortunate in having parents that attended this conference as self-appointed active listeners and productive members. Their assertions and concerns were voiced with gusto as they agreed with the perceptions of parent/consumers in the New Dimensions in Community Services Project, presented to conference participants by Ms. Beverly Morgan. Parents supported the program of the Federation for Children with Special Needs. A parent presented a "consumer paper" to the group that I have appended to this report.

In order to provide for the development of manpower, there must be effective programs developed for the vocational and occupational training for the mentally retarded. The aim of vocational training and on-the-job training should be employability. Much more remains to be done in integrating school programs with the needs of the individual and the community. More retarded children can learn the kinds of personal and job skills that will enable them to support themselves or to contribute to their own support. To accomplish this, more attention needs to be given to the whole area of job training. Beyond this, there must be adequate provision for job placement and replacement when necessary, and counseling during the process of placement and adjustment.

State plans under P.L. 94-142 will mandate special attention if parent and all educational personnel are going to understand this law and its implications. Every strategy - workshops, seminars, conferences, courses, etc., must be utilized to meet this need for parents and community. Parents may be used as para-professionals in roles of teaching and dissemination of pertinent information of P.L. 94-142.

Black colleges have been conspicuously absent in the thrust of meeting the vocational needs of many students in our society that would best be served by specific vocational programs. It is believed that there should be a specific charge given to these institutions to re-activate many of their vocational programs and such programs would be of reciprocal advantage to the colleges and later to the society as a whole.

1. Programs would provide for the retained, peer role models.
2. Self-concept and pride would be enhanced by affiliation with adults and an institution of "esteem" in the community.

3. The program could become a laboratory for experimential foci for departments of sociology, psychology, student teachers, counselors, etc.
4. Courses in Sociology, multicultural studies, behavioral sciences, and counseling could be enhanced by the establishment of family counseling centers at the college and/or satellite centers in the community and especially large urban communities.
5. Colleges could help the communities become more acceptable to the problems of the retarded. Through education, much can be done to improve the communities' understanding of these problems. In the end, all programs for the retarded will stand or fall on whether the community understands and accepts that retardation is their problem too.
6. Colleges must link-up with public school systems and provide staff development and technical assistance to identify business and education. It is on the college campus where new and controversial issues can be discussed and re-channelled into creative challenges in search of truth.
7. Colleges are ideal potential employers for the mildly retarded. Life-long learnings would be accessible to the adult retarded citizen located in a dynamic environment where change is constant.
8. Black colleges steeped in the knowledge of the Black experience with a heritage of developing "raw human resources" must realize the "explosion" of new human needs and diversities that must be targeted for professional exploration for solutions to the needs of the majority and minority populations. Special incentives and assistance should be provided to institutions for developing extended programs in education for the handicapped of all types.
9. Encourage each profession to examine, define and assess its role in serving the adult handicapped citizen. This could be done by developing PCMR "fellows" interns or externs sponsored by professional organizations to work for one year, for the purpose of developing position papers from the professionals, legal, medical, social workers, etc.
10. Surplus teachers should be given aid to return to school and maximize their basic skills with technical skills for working with the minority child.

ISSUES AND SOLUTIONS

Issue: Some states are avoiding the terms of P.L. 94-142 because their state law does not mandate services and education to include prenatal care through age 21.

Solution: Advocacy groups to push for enactment, within such states, for legislation making their range for education and services to include prenatal preventive care through age 21.

Issue: There is often lacking any community agency to coordinate and disseminate information related to services for the retarded.

Solution: Encourage the establishment of an Office for the Handicapped within each local government, where personnel of such an office will serve as ombudsmen and advocates for the retarded.

Issue: Parents and members of families of retarded persons in low economic and/or minority multicultural groups are often unaware of their rights and available services.

Solution: As a follow-up of early screening and diagnostics, the public school social worker, or other appropriate personnel, should make a home visitation to parents of the retarded to identify their special needs and make known the resources available to them.

Issue: Industry is often reluctant to train and/or hire the retarded for fear that their profit motive will not be fulfilled.

Solution: (1) Increase funding for and activities of the "Projects with Industry" programs of the Rehabilitation Act of 1973. (2) Provide special tax incentives for businesses and industry providing on-the-job training and/or employment for the retarded. (3) Teach industry how some of their processes can be simplified and performed adequately by the retarded.

Issue: There is a shortage of personnel trained to serve the special needs of the minority disadvantaged mentally retarded.

Solution: In the training of personnel to serve this unique group, include in their training the following: (1) Practicums in schools, clinics, VAFs, etc., where the group is served. (2) Case study involvement with the home and family of such group members. (3) Practicum at an agency involved in comprehensive community services for the retarded.

Issue: Such retarded persons are usually unable to learn by conventional instructional methods.

Solution: Develop sequential and simplified techniques involving minimal verbalizations and/or comprehension of the printed word, capitalize on demonstration, colors and symbols. Check instructional methods used by parents of these retarded persons.

Issue: There is often a lack of clearly indicated vocational potential of such retarded persons.

Solution: Schools should include, as part of their "appropriate" education, effective work evaluation programs along with meaningful vocational training in the community as part of the school curriculum. In addition, the curriculum should include instruction and training in skills of daily living - i.e., shopping, grooming, driving and/or riding buses, feeding and nutrition, banking, etc.

Issue: Technical assistance is often lacking in meeting special emerging needs of the disadvantaged mentally retarded.

Solution: (1) Ensure that the DD Technical Assistance Centers are properly equipped to assist in meeting such needs with (a) information, (b) training programs for service providers, (c) consultant services in the field, (d) a toll-free hot line for use by the retarded and those serving the retarded; and (e) rendering active assistance to groups seeking grant assistance for services on behalf of the retarded. (2) Establish local technical assistance offices in nearby colleges and universities equipped to provide such assistance; (3) Ensure that a national clearinghouse for information is equipped to serve the special information needs of the disadvantaged/minority retarded groups.

GROUPS 4A & 4B

LEGAL AND HUMAN RIGHTS: LEGISLATIVE AND JUDICIAL ISSUES

Discussion and Summary

All persons are entitled to life, liberty and the pursuit of happiness as guaranteed by the Constitution. These rights include exposure to a qualitative environment disigned to insure appropriate educational services, adequate housing, proper medical care, equal employment opportunity, nurturing and familial or surrogate experiences which combine to influence the physical and mental well being of all citizens.

It is, therefore, recommended by the Legal and Human Rights, Judicial and Legislative Workgroups that:

1. The practices of segregating and otherwise discriminating against persons on the basis of type or degree of physical or mental handicaps should be ended forthwith. In order to accomplish this end, it is necessary to:
   a. End the tradition of segregated housing patterns whereby mentally retarded persons and other individuals with developmental disabilities are routinely institutionalized in facilities which are separate and apart from those facilities provided for "normal" citizens;
   b. Repeal or otherwise eliminate statutes and informal procedures which permit the confinement of persons on the basis of type or degree of physical or mental handicap;
   c. Develop appropriate community based residential and programmatic services adequate to meet the needs of all citizens, including those who are mentally retarded, and which are designed to promote:
      (1) The full integration of all persons without regard to type or degree of physical or mental handicap; and
      (2) The elimination of the effects and vestige of past discrimination based on type or degree of physical of mental handicap.
2. Incentives for the creation and maintenance of community based facilities should be developed. Specifically:
   a. Funding should be made available for the development of such services as alternatives to institutionalization;
   b. Adequate research and planning should be devoted to increasing acceptance of physically or mentally handicapped individuals into the community at large;
   c. Eliminating employment barriers related to the unavailability of public transportation due to architectural barriers; and
   d. Eliminating zoning codes which have a discriminatory effect persons with physical or mental disabilities.
3. In providing generic services, procedures should be instituted to insure that: assessments of skills and handicaps are sen-

sitive to racial, socio-economic, ethnic and cultural differences, as well as the functional level of tested individuals.

4. Although there exists adequate legislative protection with regard to educational services, full implementation of such rights will not be achieved unless the following procedures are instituted:
   a. The establishment of a procedure of dissemination by school systems of information concerning the rights of persons to educational services in clear and simple language by means of television, radio, circulars and other appropriate means, as well as conducting seminars and open forums in the individual neighborhoods;
   b. The establishment of procedures by which school systems are required to identify, seek out and inform parents and consumers of the right of handicapped individuals to educational and vocational services (P.L. 94-142);
   c. The establishment of a system for providing PTA's, allied orgainzations and other advocacy groups of the rights of handicapped persons to educational and vocational services;
   d. The establishment of a system by which both professional and lay persons be educated to the issues related to the mentally retarded;
   e. The establishment of a system by which all teachers are required to take courses in special education as part of their teacher certification procedures.
5. A system should be established to insure the enforcement of existing building and housing codes regulating the use of lead based paint.
6. Procedures should be established to teach public school students, especially, those in grades 5-12, the effects of good nutrition, drug and alcohol usage, and early pregnancy on mental retardation.
7. The warning on cigarette packaging should be expanded to warn women of the dangers of smoking to fetal growth and development.
8. The establishment of a system of genetic counseling which should be routinely available to all persons considering marriage and parentage.
9. A system of limited guardianship, frequent review of the guardianship status, and appointment of guardians should be substituted for the present system of declaring persons incompetent and imposing total guardianship on persons when such is often overly restrictive of the individual's rights.
10. Establishment of administrative systems to identify and resolve interdepartmental and interagency problems which interfere with the implementation of individuals' rights and services.

REPORT TO THE PRESIDENT'S COMMITTEE ON

MENTAL RETARDATION

by

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X57634

December 29, 1977

The President's Committee on Mental Retardation, in cooperation with Norfolk State College/Department of Special Education, convened a National Multicultural Seminar on Mental Retardation Among Minority Disadvantaged Populations, at the College in Norfolk, Virginia, in October 1977. Approximately 500 persons participated in the three-day Seminar. The purposes of the Seminar were to address the major issues related to impaired and retarded human development associated with the environmental conditions of racial and ethnic discrimination, poverty, deprivation, family disruption, and consequent disadvantage; and develop recommendations and strategies for affirmative action toward reduction of the prevalence of retardation associated with these conditions.

It was a working conference dealing with policy issues and practical recommendations for program models for implementation. The major subjects addressed by speakers, panelists, and in workgroup discussions were: 1.) Prevention of retardation from environmental causes, (a) related health issues, and (b) socio-cultural, community issues; 2.) Economic and political issues; 3.) Programmatic concerns and the resources needed, (a) issues in service delivery-education, mental health, social services, related services, and their coordination, (b) issues related to manpower training and technical assistance, with special emphasis on utilization of the resources of colleges and universities with a Black Heritage; 4.) Legal and human rights for economically-socially-educationally disadvantaged persons with mental retardation, (a) legislative, and (b) judicial issues.

A series of action recommendations was developed from each of eight workgroups, for short term and long range implementation. PCMR in cooperation with Norfolk State College is engaged in the process of editing the Proceedings for several types of publications for wide distribution. Plans also call for potential regional and local follow-through activities.

If there are questions, or additional information needed regarding any of the above information, please advise.

★U.S. GOVERNMENT PRINTING OFFICE: 1979 O— 281-683/9041